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# **PAIN IN HIV/AIDS: CHARACTERISTICS, CONTRIBUTING FACTORS AND THE EFFECTS OF A SIX-WEEK PEER-LED EXERCISE AND EDUCATION INTERVENTION**

**Romy Elizabeth Parker**

**Thesis Presented for the Degree of  
DOCTOR OF PHILOSOPHY  
in the Department of Psychiatry and Mental Health  
Faculty of Health Sciences  
UNIVERSITY OF CAPE TOWN**



**Supervisors:**

Professor D. J. Stein

Professor J. Jelsma

**May 2013**



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# Abstract

**Title:** Pain in HIV/AIDS: characteristics, contributing factors and the effects of a six-week peer-led exercise and education intervention.

**Author:** Romy Elizabeth Parker

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The central premise of this thesis was that pain is a problem in persons living with HIV/AIDS (PLWHA), that this pain is biopsychosocial in nature, and as such may have different characteristics in different sub-groups. It was also hypothesised that pain in PLWHA can be effectively managed using a biopsychosocial treatment. The thesis consists of six main components. Firstly, a theoretical framework for pain as a biopsychosocial phenomenon is presented. Secondly, a systematic review of pain in HIV/AIDS was conducted. Thirdly a study to identify and translate appropriate measurement instruments to explore pain from a biopsychosocial perspective in amaXhosa women living with HIV/AIDS was performed. This was followed by validation of the measurement instruments for use in amaXhosa women living with HIV/AIDS. The fifth component was a cross-sectional study to determine the prevalence, characteristics and contributing factors to pain in amaXhosa women living with HIV/AIDS. The final component was a single-blind randomised controlled trial to determine the effectiveness of a six-week peer-led exercise and education intervention in amaXhosa women living with HIV/AIDS and experiencing pain. The findings of the systematic review suggest that pain is a problem in PLWHA, with prevalence rates of over 50%. The biopsychosocial nature of pain was evident in these data with several psychosocial factors identified as contributing to pain. Suitable measurement instruments were identified and where necessary translated for use in amaXhosa women living with HIV/AIDS. These were found to have acceptability, and appeared to be valid and reliable when used in amaXhosa women living with HIV/AIDS. Pain was present in 74% of the 229 amaXhosa women interviewed in the cross-sectional study to explore pain in this group. The pain was of moderate severity and interference and only two (1%) of the 170 women with pain were receiving adequate pharmacological management of their pain. No disease parameters were found to be associated with pain but several psychosocial variables were associated with pain. Finally, participating in a study to determine the effects of a biopsychosocial six-week peer-led exercise and education intervention using a workbook was found to significantly reduce pain severity and pain interference in amaXhosa women living with HIV/AIDS and having pain. The findings of this thesis confirm that pain continues to be a problem for PLWHA despite anti-retroviral treatment. Further, they support the premise that pain in PLWHA is biopsychosocial in nature and as such will respond to treatments based on this paradigm.



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# Abbreviations

<b>ART</b>	Anti-retroviral treatment
<b>ATN</b>	Antiretroviral Toxic Polyneuropathy
<b>BDI</b>	Beck Depression Inventory
<b>BPI</b>	Brief Pain Inventory
<b>CTQ</b>	Childhood Trauma Questionnaire
<b>CHC</b>	Community Health Centre
<b>d4T</b>	Stavudine anti-retroviral drug
<b>ddC</b>	Zalcitabine anti-retroviral drug
<b>ddl</b>	Didanosine anti-retroviral drug
<b>DSP</b>	Distal Symmetrical Polyneuropathy
<b>EQ-5D™</b>	Standardised health related quality of life measurement instrument trade-marked to the EuroQuol Group
<b>HIV/AIDS</b>	Human Immuno-deficiency Virus/ Acquired Immune Deficiency Syndrome
<b>HIV-SN</b>	HIV Sensory Neuropathy
<b>HRQoL</b>	Health Related Quality of Life
<b>HTS</b>	Harvard Trauma Scale
<b>ICF</b>	International Classification of Functioning, Disability and Health
<b>IDU</b>	Intra-venous drug use
<b>IMPACT</b>	Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials

<b>IP</b>	In-patient
<b>IRIS</b>	Immune Reconstitution Inflammatory Syndrome
<b>NRS</b>	Numeric Rating Scale
<b>NRTI</b>	Nucleoside Reverse Transcriptase Inhibitor
<b>OI</b>	Opportunistic Infection
<b>OP</b>	Out-patient
<b>PIS</b>	Pain Interference Scores
<b>PLWHA</b>	People Living with HIV/AIDS
<b>PMI</b>	Pain Management Index
<b>PSS</b>	Pain Severity Score
<b>PTSD</b>	Post Traumatic Stress Disorder
<b>SE</b>	Self-efficacy
<b>VAS</b>	Visual Analogue Scale
<b>VRS</b>	Visual Rating Scale
<b>WBPAQ</b>	Wisconsin Brief Pain Questionnaire
<b>WHO</b>	World Health Organisation

# Chapter 1: Introduction

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## 1.1 Background

The human immunodeficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS) have had a devastating impact worldwide with the developing countries\* of Sub-Saharan Africa bearing the brunt of the pandemic. The 2011 UNAIDS Fact Sheet<sup>1</sup> reported that in South Africa there were an estimated 5.6 million people infected with the virus, more people than in any other single country. Although the incidence of HIV in South Africa has dropped from 2.4% in 2001 to 1.5% in 2009, the rollout of anti-retroviral treatment (ART) has resulted in an increased prevalence with growing numbers of people living with the condition<sup>1</sup>.

In countries where ART has been made available, the profile of HIV/AIDS has changed from that of a terminal illness to one of a chronic debilitating disease which has the potential to become terminal<sup>2</sup>. With ART becoming available to people living with HIV/AIDS (PLWHA) in South Africa, a similar transition can be expected with growing numbers of PLWHA living for longer periods of time. Once the challenge of averting death from a disease is met the next step is to maximise quality of life for those living with on-going symptoms<sup>3</sup>. Research is then driven by the need to gain further insight into symptoms which persist and interventions which address these symptoms effectively to enhance quality of life and minimise symptom impact. In PLWHA, on-going symptoms are wide ranging and include pain, anxiety, nausea, vomiting and fatigue; with pain being one of the most commonly reported symptoms in studies conducted around the globe<sup>4</sup>.

Pain has been reported as the second or third most commonly reported symptom in PLWHA, both receiving and not receiving ART respectively. This has been recorded in studies conducted in Denmark<sup>5</sup>, France<sup>5,6</sup> Australia<sup>7</sup>; USA<sup>8</sup> Italy<sup>9</sup>; Thailand<sup>10</sup>; South Africa<sup>11,12</sup> and the region of Southern Africa<sup>13</sup>. These studies have highlighted both the prevalence of pain as a symptom, and its inadequate management as PLWHA often receive either too little or no analgesia at all<sup>5,12-14</sup>.

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\* The World Bank classifies countries with low and middle income economies as developing countries. South Africa is classified as an upper middle income economy with a per capita gross national income of US\$4036 – US\$12475 in 2011.

Although some data on pain in PLWHA in South Africa is available, previous studies have focused on specific segments of society and relatively little is known about the prevalence of pain in amaXhosa<sup>†</sup> living with HIV/AIDS. Further, while the under-management of pain in some groups of South Africans living with HIV/AIDS has been noted<sup>12 15</sup>, there is a paucity of literature presenting effective pain management strategies for these patients. To facilitate a full understanding of pain as a symptom and an experience in PLWHA, the International Classification of Functioning, Disability and Health<sup>16</sup> (ICF) is proposed as a conceptual framework for the biopsychosocial model of pain.

## 1.2 Pain – a theoretical framework

The ICF was approved by the World Health Organisation in 2001 as the theoretical basis for defining and measuring health and disability<sup>16 17</sup>. The ICF is based on a conceptual model which integrates the biomedical and societal models of functioning and disability, with an emphasis on health and functioning<sup>18</sup>. In the development of the ICF, it was recognised that both the biomedical and societal models of health and disability have limitations<sup>16</sup>. In the biomedical model, functioning and disability are viewed as a direct consequence of disease. Within the biomedical model, disability is managed by treating the disease. Although the biomedical model is appropriate in some instances, it is limited. For example in many painful musculoskeletal conditions the underlying disease or disorder cannot be identified and the level of disability which arises is varied with little relationship to the severity of the underlying biological contributors<sup>18</sup>. In the societal model of disability, it is society which creates the disability for the individual rather than disease<sup>16</sup>. In this model, disability is managed within a social context requiring policy changes which affect the physical and social environments which impact on the functioning of the individual. This model is limited as it fails to recognise the role that illness may have in contributing to disability.

The ICF essentially combines the biomedical and social models into a biopsychosocial model of health (Figure 1-1). The ICF integrates the biological, individual and social factors which contribute to functioning<sup>19</sup>. Exploring pain within the ICF framework as a biopsychosocial concept provides insight into the pain experience of the individual<sup>19</sup>.

Pain is a simple word used to describe a complex experience. Pain has been defined as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. Pain is always subjective'<sup>20 (p. 210)</sup>. From this definition pain is clearly influenced by multiple interacting variables. Pain is associated with body functions and structures, personal emotions and environmental or social factors. Pain impacts on activity and participation and is equally influenced by them. As clearly illustrated by the ICF framework in Figure 1-1, pain is a biopsychosocial event unique to the individual<sup>21 22</sup>.

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<sup>†</sup> The Xhosa are the largest cultural group in the Western Cape province of South Africa with a population of approximately nine million people. Members of the Xhosa refer to themselves as amaXhosa while the language is referred to as isiXhosa. IsiXhosa is the second most common home language in South Africa after isiZulu.

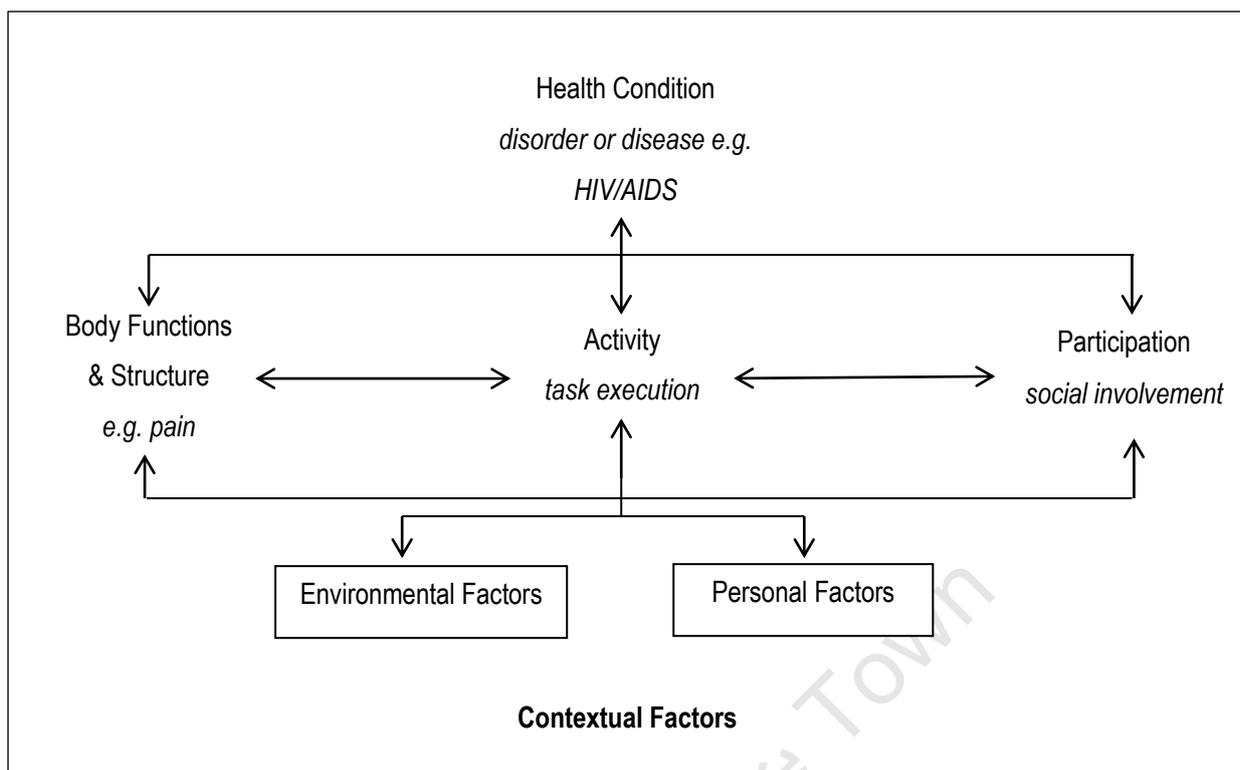


Figure 1-1: Diagrammatic representation of the ICF

Pain, originating from and/or impacting on body functions and structure has a biological component involving cortical processes. The social consequences of pain often include limited activity and participation. However, these factors are not simply the effects of pain; they may equally be contributors to pain with limited social support and activity known to be associated with increased pain<sup>19</sup>. Similarly, personal psychological factors may both occur as a consequence of pain or as contributors to pain<sup>23</sup>. People in pain commonly avoid activity, report symptoms of depression and withdraw from social contact. Conversely, depressive symptoms and withdrawal from society are known to contribute to pain.

Pain, therefore, is a multifaceted biopsychosocial experience, influenced by and influencing many diverse components of the sufferer's life. The integration of the biological and psychosocial components which lead to the pain experience result in each individual's perception of, and response to pain, being unique<sup>21 22</sup>. In a complex illness such as HIV/AIDS, understanding the multifaceted nature of pain is essential for its effective management in PLWHA, whose illness itself as well as other personal or environmental (psychosocial) factors may contribute to symptoms of pain. Using the ICF as a framework for the biopsychosocial model of pain provides a structure within which the characteristics and contributing factors to pain in PLWHA can be explored, in addition to guiding the development of management strategies for pain in PLWHA.

## 1.3 Outline of this thesis

In this thesis, a series of studies will be presented which describe the characteristics, contributing factors and management of pain in PLWHA with particular reference to amaXhosa women living with HIV/AIDS. The specific objectives of the research were to:

1. Determine the prevalence of pain in PLWHA by means of a systematic review.
2. To identify, describe and, where necessary, translate appropriate measurement instruments to explore the characteristics and factors contributing to pain in amaXhosa women living with HIV/AIDS.
3. To determine the validity and reliability of measurements instruments to explore the characteristics and contributing factors to pain in amaXhosa women living with HIV/AIDS.
4. To determine the characteristics and factors contributing to pain in amaXhosa women living with HIV/AIDS.
5. To develop and test an intervention for the management of pain in amaXhosa women living with HIV/AIDS.

The thesis is presented in seven further chapters:

### 1.3.1 *Chapter 2: Causes of Pain in HIV/AIDS*

In this chapter, background on the HIV/AIDS epidemic in South Africa is provided to contextualise the research presented in the thesis. This is followed by a review of the causes and current best management of pain in PLWHA.

### 1.3.2 *Chapter 3: Pain in people living with HIV/AIDS; a systematic review*

As previously mentioned, several studies have reported on the prevalence of pain in PLWHA, both receiving and not receiving ART, in a variety of settings. However, many of these studies were conducted on small non-generalizable samples limiting their broad applicability. In order to expand on the scale and nature of the problem of pain in PLWHA the data from these various studies needs to be pooled. In Chapter 3, a systematic review of studies reporting on the prevalence of pain in PLWHA at all stages of the disease and in those both receiving and not receiving ART is presented. In addition to presenting the prevalence of pain in PLWHA, characteristics, contributing factors and the management of pain are explored.

### *1.3.3 Chapter 4: Instrumentation – selection and translation*

In order to answer a research question robust measurement and assessment approaches are required which are valid in the chosen study setting. The aim of this chapter was to describe the process of selecting appropriate measurement instruments for the study of pain in amaXhosa women living with HIV/AIDS; a process informed by factors identified in Chapter 3 and the biopsychosocial model of pain. The chapter is presented in two parts. In the first part of the chapter, a description of and the motivation for selecting measurement instruments to describe the prevalence, characteristics and contributing factors to pain in amaXhosa women living with HIV/AIDS is presented. In the second part of the chapter, the framework, process and outcome of the translation of those instruments not available in isiXhosa is presented.

### *1.3.4 Chapter 5: Instrumentation – validity and reliability*

Effective research relies on valid and reliable measurement instruments<sup>24</sup>. In a continuation from Chapter 4, data for the validation of the newly translated instruments is presented. In addition, studies to confirm the reliability of all the instruments used in the study exploring pain in amaXhosa women living with HIV/AIDS are presented.

### *1.3.5 Chapter 6: Pain in amaXhosa women living with HIV/AIDS*

According to the biopsychosocial model of pain, the experience and impact of pain may differ across cultural and ethnic groups. Thus, although a systematic review of pain in PLWHA will provide broad insight into the problem, there is value in exploring pain in target groups to inform management. In this chapter, the prevalence, characteristics and contributing factors to pain in a group of amaXhosa women living with HIV/AIDS in a resource poor area of Cape Town are presented. The chapter identifies the prevalence and characteristics of pain such as pain severity and interference and pain sites in these women. In addition, the pain management in this group is presented. The chapter concludes by exploring the role of the various biopsychosocial variables which may impact on pain.

### *1.3.6 Chapter 7: The effects of an intervention programme on pain in amaXhosa women living with HIV/AIDS*

An understanding of the prevalence of pain and the factors which contribute to pain is informative but this information needs to be translated into clinical practice where it will have an impact on patient suffering. In this chapter of two parts, a clinical intervention for the management of pain in PLWHA is presented and tested.

In the first section, the composite components of an intervention programme designed on the basis of the data in the preceding chapters and on chronic disease and chronic pain management approaches, is presented. In the second part of the chapter, the results of a single blind randomised controlled trial to test the effects of this intervention are reported.

### *1.3.7 Chapter 8: Conclusion*

In the final chapter of the thesis the appropriateness of the biopsychosocial model for use in PLWHA with pain is defended. A summary of the data from the thesis is presented and the chapter concludes with recommendations for further research. Finally the clinical implications and applications of the research presented in the thesis are discussed.

## Chapter 2: Causes of Pain in HIV/AIDS

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To provide context for the research presented in this thesis, it is useful to reflect on the history of the pandemic and the management of HIV. In this chapter, a profile of HIV/AIDS in South Africa will be presented followed by a summary of the history of the HIV/AIDS pandemic in South Africa. Finally, the causes and current best management of pain in PLWHA, one of the most common symptoms associated with the virus, will be discussed.

### 2.1 Profile of HIV/AIDS in South Africa

South Africa has an estimated 5.6 million people living with HIV/AIDS (PLWHA), the largest HIV+ population in the world<sup>1</sup>. There are disparities in the prevalence of HIV/AIDS across South Africa. In the Western Cape Province, where the research reported in this thesis was conducted, the prevalence of HIV/AIDS in the 15 – 49 age group is estimated to be less than 5.5%. However, in other provinces the prevalence rises to over 18% in the same age range<sup>25</sup>. Prevalence rates in pregnant women are similarly diverse, with rates in some communities being as high as 40% while in neighbouring community clinics rates drop to less than 1%. From the current data, it appears that the epidemic in South Africa is worst in resource poor communities where infrastructure is lacking. Despite the relatively low prevalence rates in the Western Cape, the amaXhosa predominate in this province. As highlighted in Chapter 1, relatively little is known about the prevalence of pain in amaXhosa living with HIV/AIDS. It is relevant therefore to conduct research in the Western Cape with specific focus in amaXhosa living with HIV/AIDS.

In South Africa, adults are most affected by the virus with 15.6% (95% CI 14.2 – 17.1) of those aged between 25 and 49 years living with HIV/AIDS<sup>26</sup>. Inclusion of young adults (15 – 25y) in this group further increases the prevalence rate to 16.2% (95% CI 14.9 – 17.7). Further, the prevalence is higher among females than males in the 20 – 24y (23.9% vs. 6%); 25 – 29y (33.3% vs. 12.1%) and 30 – 34y (26% vs. 23.3%) age groups and in total (13.3% females HIV+ vs. 8.2% males). Black South African's are the population group most affected by HIV<sup>26</sup>. Young adult black South African women are therefore the segment of the population most affected by the pandemic.

The number of new infections of HIV/AIDS in South Africa has decreased from a peak of 750 000 in 1998 to less than 500 000 in 2008<sup>25</sup>. The number of deaths associated with AIDS peaked in 2006 at nearly 400 00 per annum and has been gradually decreasing since that time. These figures are underpinned by a rise in the number of people on ART, 40% of PLWHA with CD4+ < 350 were estimated to be receiving ART in 2009 and nearly 60% of this group received ART in 2010<sup>1</sup>.

However, despite gains, when the worldwide data are consulted, nearly half of the deaths from AIDS-related illnesses in 2010 occurred in the southern African region. While the situation in South Africa is improving, the pandemic still places a high burden on the country and the region compared with the rest of the world<sup>1</sup>.

There are ten different patterns of the HIV/AIDS epidemic around the world<sup>27</sup>. While clade subtype B predominates in North America and Western Europe, subtype C, the dominant form of the virus worldwide, is the most common form of the virus occurring in South Africa. However, it should not be presumed that subtype B does not occur in the region, rather, it appears that there may be independent epidemics with virus subtypes being specifically associated with mode of transmission. In South Africa, subtype B has been found to be associated with homosexual transmission while subtype C has been associated with heterosexual transmission<sup>28</sup>. It has been proposed that different subtypes of the virus present with different symptom patterns<sup>29</sup>. This reinforces the need to conduct research in specific social groups in which different viral subtypes predominate. A summary of the history of the country in the context of the rise of HIV/AIDS will now be presented to develop an understanding of some of the variables which may have contributed to the acceleration of the epidemic in South Africa.

## 2.2 History of HIV/AIDS in South Africa

The first two cases of AIDS in South Africa were reported in 1983<sup>30</sup>. Initially the disease spread slowly in the South African population, and by 1990 when the first national antenatal survey was conducted, it was estimated that less than 1% of pregnant women were infected. However, the infection rates in the antenatal survey rapidly rose from this point in time to 10% in 1995, 24% in 2000 to 30% in 2005. Between 2006 and 2009 the prevalence rates in pregnant women appear to have stabilised at 29%<sup>31</sup>. While there is some controversy surrounding the prevalence rates in South Africa based on the methodological approach of the epidemiological studies, in 2010 it was estimated that 5.6 million or just under 20% of South Africans were infected<sup>1</sup>. An understanding of South Africa's political history provides insight into the emergence of the pandemic and its subsequent stabilisation.

In 1983 when the first cases of AIDS were reported, South Africa was ruled by an apartheid government which was being vigorously challenged. The system of apartheid resulted in the weakening and breakdown of extended family connections and community structures in an environment where there was unequal distribution of wealth with the majority of the population not having access to clean water, electricity, education or healthcare<sup>32</sup>. This had a negative effect on the social structure of the nation and deleteriously impacted on social cohesion<sup>‡</sup>.

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<sup>‡</sup> Social cohesion can be regarded as the connections which unite people within a society from familial ties, to community, cultural and national bonds.

Barnet and Whiteside<sup>33</sup> propose that a loss of social cohesion is a primary driver in the spread of the AIDS pandemic in South Africa. However, the spread of the pandemic cannot be completely attributed to South Africa's apartheid history.

In 1985, the year of the first AIDS related death in the country, a national state of emergency was declared in response to increasing riots, unrest and protest against apartheid. This state of emergency lasted five years and although the apartheid government of the day formed an AIDS advisory group to address the growing burden at this time, its work was hampered by the political climate, violence and conspiracy theories about the disease generated by both sides of the political spectrum<sup>34 35</sup>. These conspiracy theories ranged from AIDS being created by the apartheid government as a form of biological warfare to right wing supporters of apartheid proposing that AIDS was designed to kill white South Africans<sup>36</sup>.

It was in this context that the country entered a period of transition to democracy starting in 1990 with the release of Nelson Mandela. At this time, AIDS was once again brought to the attention of the public and the government<sup>27 35 36</sup>. The many organisations involved in the liberation movement including the African National Congress (ANC); the Congress of Trade Unions (COSATU) and the United Democratic Front (UDF) all raised their voices on the subject of AIDS and in May 1990 a National AIDS Task Force was established. It was during the transition period, in 1992, that the National AIDS Coordinating Committee of South Africa (NACOSA) was formed to develop a national strategic plan for the management of AIDs. The objective being that the plan would be rolled out when the new government took power. NACOSA developed a National AIDS Strategy within a year of being formed and this strategy was adopted by the new, democratically elected government in 1994<sup>35 36</sup>.

With the adoption of the National AIDS Strategy it appeared that South Africa was set to avoid following the route of its neighbours where high prevalence rates and mortality were decimating populations<sup>27</sup>. However, this was not to be the case and by 2000 South Africa had the fastest growing epidemic in the world<sup>34</sup>. Several authors have theorised that the reasons for the initial failure of the strategy included loss of social cohesion and poverty in the majority of the population<sup>33</sup> lack of political will<sup>27 36</sup>, prioritizing of several restructuring and development programmes such as housing, education and job creation and the devolution of power to provincial governments resulting in a breakdown of the national strategy<sup>34</sup>.

The initial failure of the AIDS Strategy was compounded by contradictory, false and confusing stances presented by the government<sup>27 36</sup>. In 1998, the AIDS advisory committee was dismissed and in 1999, the Department of Health decided not to provide AZT to pregnant women or survivors of rape<sup>34</sup>, despite evidence that this could halve mother to child transmission rates<sup>37 38</sup>. Then, in 2000, the Department of Health presented a five year plan for AIDS and HIV and established a National AIDS Council<sup>36</sup>, apparently recognising the need to take decisive action. However, continued lack of political will resulted in continued delays in the delivery of treatment.

The government finally approved a treatment programme in 2003 with the aim of having 54 000 people on ART by March 2004 and a million people on treatment by 2008<sup>36</sup>. Initial rollout of ART was accelerated in 2005 when funding from the Global Fund and the United States President's Emergency Plan for AIDs Relief (PEPFAR) was realised<sup>36</sup>. External funding at this time funded over half of patients receiving ART in the public sector. However, the rollout of the programme was slow, beset by administrative challenges, delays in the provision of treatment guidelines and a lack of spending of resources allocated to the programme by the treasury. This was compounded by the department of health failing to negotiate with drug companies over drug prices<sup>36</sup>. By 2006, ART programmes had been launched in all of South Africa's provinces, although with varying success with only 12% of those eligible for treatment receiving it<sup>36</sup>. The rollout of these programmes was specifically accelerated by the provision of funds from external donors.

Co-ordinated provision of ART with the involvement of civil society became a reality in 2008 when the government adopted a visible rollout strategy - the National Strategic Plan for 2007-2011<sup>39</sup>. To date, it is estimated that 60% of PLWHA in South Africa eligible for ART are receiving treatment. Although access to treatment is variable across provinces, the improvement in the delivery of health care for PLWHA is viewed as a principal reason for the present stabilising of the epidemic in South Africa<sup>40</sup>.

Despite the apparent stabilising of the spread of the epidemic, the country still has to continue to support the nearly 6 million citizens living with HIV/AIDs. This entails continuing monitoring and treatment for people living with a chronic disease with its many symptoms including pain. Pain in HIV/AIDs will now be discussed with particular reference to the causes of pain and its evidence based management.

## **2.3 Pain in HIV/AIDs**

The most common symptoms experienced by PLWHA in Southern Africa are fatigue and pain. These are followed by diarrhoea, rashes and coughs<sup>13 41 42</sup>. In Southern and South African populations, the problem of pain in PLWHA has been recognised, but its under-management continues<sup>43</sup>. Pain, as discussed in Chapter 1, is a complex symptom which can arise from various sources and be exacerbated by a multiplicity of variables.

The types of pain experienced by people with HIV/AIDs and the aetiology of such pains are varied. PLWHA may experience pain as a direct result of the virus; pain may be due to immune suppression and resultant opportunistic infections (OI); or pain may arise due to immune reconstitution inflammatory syndrome (IRIS). Pain may be a result of the side effects of ART, be idiopathic in origin or be due to other illnesses not associated with HIV<sup>44-46</sup>. The type of pain which arises is, alone, not diagnostic of its cause, for example painful peripheral neuropathies may be caused by the virus or be a consequence of ART<sup>45</sup>. In the following section, pain will not be discussed defined by cause; rather, the most common types of pain and their possible causes will be presented.

The approach of focussing on type of pain allows the researcher and clinician to evaluate symptoms as they would present clinically using a biopsychosocial framework. Analysis of pain in this manner takes into account all possible causes and ramifications.

### 2.3.1 Headaches

Headaches have been reported to occur in 50% of PLWHA<sup>46</sup>. The causes of headaches in this population range from tension headaches and migraines, drug induced headache (commonly with AZT), malignancy, OI such as cytomegalovirus encephalitis or the headache may be directly caused by the virus such as in HIV meningitis<sup>45</sup>. In patients with CD4+ > 200cells/microL and suffering headaches, it is likely that the headache is idiopathic in origin. However, in immune-compromised patients the headache may be a symptom of infection or malignancy and should be fully investigated<sup>47</sup>.

### 2.3.2 Pain in the Gastrointestinal Tract

As with headaches, pain in the gastrointestinal tract (GIT) occurs in up to 50% of PLWHA. Pain in the GIT can be divided into oral and oesophageal pain, abdominal pain and anorectal pain.

#### 2.3.2.1 Oral and oesophageal pain

Painful oral and oesophageal lesions occur in up to 50% of PLWHA<sup>48</sup>. These lesions may be the results of OI such as candida, herpes, CMV and others. They may also be caused by malignancy, or be drug induced<sup>45</sup>. Rapid management of these lesions is essential as the pain often interferes with eating which further compromises the PLWHA.

Treatment of these lesions needs to include addressing the underlying cause combined with appropriate analgesic therapy. While oral analgesics are effective, local coating agents and topical analgesics may provide some relief<sup>45</sup>.

#### 2.3.2.2 Abdominal pain

Abdominal pain may arise as a treatment side effect, due to an OI, or as a consequence of malignancy<sup>45</sup>. Side effects of ART include pancreatitis, renal colic, and lactic acidosis. Acalculous cholecystitis and sclerosing cholangitis may be due to HIV infection while OI with CMV or cryptosporidium may also cause abdominal pain<sup>49</sup>  
<sup>50</sup>. Management of this pain needs to address the underlying cause combined with analgesic therapy.

### 2.3.2.3 Anorectal pain

The prevalence of anorectal pain varies across populations of PLWHA. In some groups of patients, nearly 60% have complained of anorectal pain<sup>45</sup>. Causes of pain include idiopathic anal ulcers, fistulae, abscesses and haemorrhoids, ulcers due to OI, anal warts, and malignancies. As with other pains in the GIT, the underlying cause of the symptom needs to be addressed in combination with appropriate analgesic therapy.

### 2.3.3 *Neuropathic pain*

Neuropathic pain may occur as a consequence of the virus, ART, immune suppression and subsequent OI. Several painful neuropathies are associated with HIV/AIDS including, but not limited to, distal symmetrical polyneuropathy (DSP), antiretroviral toxic polyneuropathy (ATN), acute herpes zoster pain, postherpetic neuropathy, mononeuritis multiplex, CMV polyradiculopathy and acute demyelinating polyneuropathy<sup>45 51</sup>. The clinical presentations of these conditions frequently overlap making a diagnosis difficult in the clinical setting.

#### 2.3.3.1 Distal Symmetrical Polyneuropathy (DSP) and Antiretroviral Toxic Neuropathy (ATN)

Approximately one third of PLWHA develop a DSP which presents with pain, sensory loss, paraesthesia and dyasthesia<sup>52</sup>. Almost indistinguishable from this condition is ATN, which is associated with the use of nucleoside reverse transcriptase inhibitor (NRTI) ART. The two conditions combined, DSP and ATN, are often referred to as HIV-associated sensory neuropathy (HIV-SN) and occur in over 40% of PLWHA<sup>43 45 53</sup>. In a cohort from Cape Town, South Africa, almost half the participants presented with DSP. In this group, a history of stavudine (d4T) treatment, increasing age or a history of prior tuberculosis infection were all independently associated with the presence of DSP<sup>54</sup>.

Both conditions are small fibre neuropathies which occur in PLWHA with low CD4+ counts and a history of an AIDS defining illness<sup>55</sup>. While DSP has an, at present, unknown pathogenesis; ATN is theorised to be a consequence of NRTI mitochondrial toxicity in the sensory neurones. Patients present with distal symmetrical symptoms of pain, sensory loss and paraesthesia and in the advanced stage may have motor weakness of the intrinsic muscles. As clinical examination does not distinguish between DSP and ATN, the drug history may be the only indication of the cause with the initiation of treatment with one of these drugs (stavudine – d4T; didanosine – ddI; zalcitabine – ddC) preceding symptom onset in ATN by between one week and six months<sup>45</sup>.

The management of HIV-SN is a challenge for clinicians with the majority of drugs known to be useful for neuropathies in other conditions being ineffective<sup>53</sup>. In a recent systematic review and meta-analysis, smoked cannabis, topical capsaicin 8% and recombinant human growth factor were the only treatments with greater efficacy than placebo<sup>53</sup>. Amitriptyline, gabapentin, pregabalin, prosaptide, peptide-T, acetyl-L-carnitine, mexilitine, lamotrigine and topical capsaicin 0.075% had no superiority over placebo. Further, there is a paucity of research on the effectiveness of opioids in this population but the limited evidence available suggests it has minimal effect<sup>56</sup>. In the South African context, clinicians essentially have no evidence based pharmacological tools to treat HIV-SN as topical capsaicin 8% is not available, the risks of smoked cannabis outweigh its benefits, recombinant human growth factor is unavailable for clinical use and there is a paucity of evidence to support the use of opioids in these conditions<sup>53,57</sup>.

#### 2.3.3.2 Acute herpes zoster pain and postherpetic neuralgia

Symptoms of herpes infections present ten times more often in PLWHA with increasing incidence as CD4+ counts drop<sup>45</sup>. These symptoms may occur as a consequence of opportunistic infection in the immune compromised patient or as part of IRIS when the recovering immune system responds to prior infection<sup>58</sup>. Pain arising from this opportunistic infection can be acute with more severe cases having a higher risk of developing postherpetic neuralgia. PLWHA with CD4+ <200cells/microL are at greatest risk of developing major ocular or neural complications.

The management of these conditions for PLWHA is essentially the same as for the non-HIV infected population. Effective treatments include pharmacological management with tricyclic antidepressants, strong opioids, gabapentin, tramadol and pregabalin. In addition topical treatment with lidocaine 5% patches and capsaicin are known to be effective but once again, these treatments are not available in South Africa<sup>57</sup>.

#### 2.3.3.3 Mononeuritis multiplex

Mononeuritis multiplex can present with pain and sensory or motor deficits in the distribution of a single peripheral nerve or in several separate peripheral, spinal or cranial nerves<sup>45,51</sup>. This neuropathy may present early in HIV infection as a consequence of immune responses similar to those observed in rheumatological conditions. Conversely, late in infection when CD4+ counts drop below 50, a similar presentation may be a consequence of opportunistic infection by the cytomegalovirus (CMV). Infection with CMV typically presents with cauda equina pain, paraparesis and sphincter disturbance typical of cauda equina syndrome. Treatment of this type requires a clear identification of the underlying cause with combined analgesic management of pain<sup>45</sup>.

### 2.3.4 *Musculoskeletal pain*

Musculoskeletal pain may be a direct result of the HIV, a side effect of ART, or a consequence of OI or malignancy. Arthritis of many forms commonly occurs in PLWHA with mono- and poly-articular arthralgias and arthritides presenting, particularly Reiter's syndrome and psoriatic arthritis<sup>59-61</sup>. Perhaps the most common are the septic musculoskeletal complications with some studies reporting up to 40% of PLWHA receiving ART with musculoskeletal symptoms diagnosed with septic arthritis, cellulitis, osteomyelitis and pyomyositis<sup>61</sup>. Chronic widespread pain or fibromyalgia has been reported in 11-29% of PLWHA<sup>60</sup>. Myopathies may present as a direct result of HIV infection, as a consequence of HIV wasting syndrome, or as a side effect of the drug zidovudine<sup>45</sup>.

The management of these symptoms in PLWHA is effective with application of the guidelines for the non-HIV infected population. However, careful consideration of drug interactions is needed<sup>51</sup>.

### 2.3.5 *Gynaecological pain*

In women hospitalized with HIV/AIDS, gynaecological diseases are highly prevalent<sup>62</sup> with women with HIV/AIDS presenting with higher rates of disease than non-HIV infected women<sup>63</sup>. Genital ulceration is most common as a result of sexually transmitted infections such as syphilis and CMV. Pain may also be due to malignancy or pelvic inflammatory disease<sup>45 62</sup>. Many of the gynaecological conditions which cause pain are AIDS defining reinforcing the importance of regular screening in women living with HIV/AIDS. Management of gynaecological pain requires adequate identification of the cause and good administration of analgesia<sup>45</sup>.

It is apparent that pain in PLWHA can have several causes, either acting independently or interacting. While guidelines for the management of many of these conditions exist, at this time, treatment options are limited and further research is indicated to maximise pain management options in PLWHA<sup>43 53</sup>.

## 2.4 **Summary**

The spread of the HIV/AIDS epidemic in South Africa appears to have stabilised. However, the nearly six million South Africans living with HIV/AIDS will require monitoring and support from the health services for their lifetimes. These PLWHA are likely to suffer from various types of pain with varied causes during the course of their illness. Effective pain management in PLWHA requires clinicians to be cognisant of the multiple types and causes of pain in this population, the possibility of multiple acute and chronic pains occurring simultaneously, and the emerging evidence for new pain interventions in this population. In the next chapter, a systematic review of the prevalence of pain in PLWHA will be presented. In addition to information on prevalence, variables from the literature identified to contribute to or increase risk of pain will be discussed.

# Chapter 3: Pain in people living with HIV/AIDS; a systematic review

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## 3.1 Introduction

Pain is recognised as the second most commonly reported symptom in people living with HIV/AIDS (PLWHA)<sup>45</sup>. The types of pain experienced by people with HIV/AIDS and the aetiology of such pains are varied. People living with HIV/AIDS may experience pain as a direct result of the virus on the peripheral or central nervous systems; pain may be due to immune suppression and resultant opportunistic infections; or pain may arise as a result of the side effects of anti-retroviral treatment (ART). The pain may also be idiopathic in origin with no clear aetiology or be due to other illnesses not associated with HIV<sup>46</sup>. Wide ranges of pain prevalence have been reported with figures as low as 0%<sup>64</sup> to above 90%<sup>11</sup>. With the range of prevalence rates reported, it is difficult to evaluate the relative impact of pain in PLWHA.

The problem of pain in PLWHA is exacerbated by its under-treatment. In 1994 the International Association for the Study of Pain (IASP) formed a Task Force on Pain and AIDS in recognition of the need to disseminate information on pain in AIDS with a focus on addressing the under-management of pain in PLWHA. In a 1996 review article written for the IASP, Breitbart and Passik<sup>44</sup> emphasised the prevalence of pain in PLWHA and its under-treatment. Since then, several other studies reporting the prevalence of pain in PLWHA have been published and it appears that pain is still a significant problem for PLWHA and remains under-treated. To date, no systematic review on the prevalence of pain in PLWHA has been published resulting in a lack of information on the exact prevalence of pain and the extent of its under-treatment.

In addition to accurate prevalence figures information on the severity and characteristics of the pain as well as the factors which contribute to pain would inform decisions regarding its management. Information about the functional impact of pain in PLWHA is similarly needed to plan for the support and additional management required for these patients. Finally, while the under management of pain in this population has been acknowledged, the extent of this problem is not known. Previous strategies to address the barriers to treating pain in PLWHA need to be assessed through evaluation of current treatment of pain.

The objective of a literature review is to provide a synthesis of current research which gives the researcher comprehensive information on what is known and what is not known in a specific field of research<sup>65</sup>. Narrative literature reviews use non-standardised and subjective methods to collect information.

While narrative reviews are useful to provide critiques of previous work and to highlight gaps in the literature, they are criticised for being open to bias in both assessment and processing of the literature presented. In a systematic review of the literature, specific and explicit methods are used to identify and choose literature and in the analysis of the data. The advantages of a systematic review include the rigor of the process and its reporting which increase reproducibility and limits bias<sup>65</sup>. The aim of this chapter is to present the results of a systematic review undertaken to explore the prevalence and characteristics of pain in PLWHA.

## **3.2 Objectives**

The objectives of this review were to address the following questions:

- What is the prevalence of pain in people living with HIV/AIDS (PLWHA)?
- What are the characteristics of pain in PLWHA in terms of site and severity?
- What factors contribute to the prevalence of pain in PLWHA?
- Is pain adequately managed in PLWHA?
- What is the functional impact of pain in PLWHA?

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## 3.3 Methods

### 3.3.1 *Criteria for selecting studies for review*

Criteria were identified in three categories to guide selection of studies for the systematic review.

#### 3.3.1.1 Types of studies

Descriptive cross-sectional surveys or longitudinal studies which included baseline cross-sectional data were included in the review.

#### 3.3.1.2 Participants

Surveys which included people living with HIV/AIDS at any stage of the illness including those receiving ART, inpatient and outpatient groups, adult males and females.

#### 3.3.1.3 Outcomes

Studies reporting on the prevalence of pain, characteristics of pain, factors contributing to pain, effects and consequences of pain and treatments for pain in PLWHA were included. Case-control studies, case reports, letters and studies which were conducted at pain clinics or had only included patients with pain or subgroups of painful conditions (e.g. persons suffering from painful peripheral neuropathy only) were excluded.

### 3.3.2 *Search methods*

A Medical Subject Heading (MeSH) search was conducted in PubMed to investigate search terms and assist in forming a search strategy. Search terms selected were “pain” and “HIV” or “acquired immune deficiency syndrome”. Electronic databases were selected for inclusion based on the likelihood of containing relevant information. Databases searched were PubMed (which includes Medline), Scopus (which indexes Embase); Africa-wide: NIPAD; CINAHL; PsychARTICLES; PSYCINFO; PSYCHIATRYONLINE; ScienceDirect and Web of Science. EBSCOHost was used for simultaneous searching of Africa-wide: NIPAD; CINAHL; PsychARTICLES and PSYCINFO.

A time limit of March 1982 to March 2012 was set. Limits on the searches were set to include journal articles in English, “human” and “adult”. The terms “qualitative research”; “child” or “children” or “adolescent” or “neonate”; “rat” or “rodent” or “mouse”; “random\* control\* trial” or “case study” or “case report” were excluded using the “NOT” Boolean search term.

### 3.3.3 Data extraction and quality assessment

All the citations identified were imported into Endnote® and duplicates were removed. The author and a research assistant independently screened all citation abstracts for inclusion using a piloted form developed according to the inclusion and exclusion criteria (Table 3-1). The full texts of citations identified by either the author, or the research assistant as possibly containing relevant information were obtained after duplicates were removed.

Table 3-1: Criteria for screening of abstracts

Category	Inclusion Criteria	Exclusion Criteria
<b>Population</b>	HIV+	Sub-groups of HIV+ or reporting on HIV+ with pain only
<b>Study design</b>	Cross-sectional or longitudinal studies, prevalence studies	Case reports, case studies
<b>Outcome</b>	Report on the presence of pain in the sample	Reporting a pain sub-grouping only

The STROBE guidelines for the reporting of observational studies were consulted in order to evaluate quality of the selected citations<sup>66</sup>. The STROBE guidelines did not include specific information relating to pain, thus, methodological quality critical appraisal tools used in systematic reviews of epidemiological studies of pain or painful conditions were reviewed and used to inform the development of a tool<sup>67-69</sup>. The tool examined three methodological components of prevalence studies identified in both the STROBE guidelines<sup>66</sup> and other systematic reviews of prevalence studies<sup>67-70</sup>; with 11 specific criteria (Table 3-2). Each criterion was marked as being present, absent or not applicable. Scores for each study were then calculated as a percentage. The method described by Louw et al<sup>68</sup> was utilised to select studies of acceptable standard for inclusion in the review. This entailed calculating the mean score of the studies selected, studies with scores of greater than or equal to the mean were included in the review.

Table 3-2: The 11 item critical appraisal tool

<p>A. Is the sample representative of the target population?</p> <ul style="list-style-type: none"> <li>i. Appropriate target population (HIV+ or AIDS adults)</li> <li>ii. Reasons for non-responders and or description of non-responders</li> <li>iii. Response rates stated</li> <li>iv. Description of the population including HIV/AIDS stage or provision of CD4+ count, age and sex of the sample</li> </ul>
<p>B. Methodological quality of the study</p> <ul style="list-style-type: none"> <li>i. Study design (a cross-sectional study designed to collect prevalence data)</li> <li>ii. Standardised method of data collection used</li> <li>iii. The use of validated measurement instruments</li> <li>iv. Data collected directly from the participants</li> </ul>
<p>C. Definition of Pain as a symptom</p> <ul style="list-style-type: none"> <li>i. The term "pain" operationally defined</li> <li>ii. Inclusion of specific information relating to the pain such as frequency, location, intensity and character of the pain</li> <li>iii. Prevalence recall periods stated</li> </ul>

Data was extracted from the studies and entered into spread sheets to create a summary table which included the following information: year of publication, country and setting, sample size, age and gender, disease profile of the sample, outcome measure employed, pain prevalence and recall period, severity of pain, pain interference and pain management index. Weighted mean prevalence rates of pain were calculated using the data from each of the studies. Weighted means were calculated using the formula:

$$\bar{x} = \frac{w_1x_1 + w_2x_2 + \dots + w_nx_n}{w_1 + w_2 + \dots + w_n}$$

The prevalence data was summarised, pooled for analysis and reported systematically. There were wide ranges in the prevalence data; hence the median was included to reflect the influence of outlying data.

A summary of factors identified as contributing to pain is presented. The studies reviewed used a range of methods to analyse for factors contributing pain, including multivariate analysis and various univariate and bivariate analyses. It should be noted that no distinction was made between the analytical approaches used when summarising this data.

### 3.4 Results

The online search generated 2674 potential citations (Table 3-3). On removal of duplicates, 1866 citations remained. Following screening of the abstracts, 134 citations remained and full text copies were obtained. Sixty-one studies fulfilled the inclusion criteria after full text review and were evaluated further using the 11-item critical appraisal tool. Following scoring with the critical appraisal tool, the mean score was calculated and the studies scoring greater than or equal to the mean were included in the review. The flow diagram of the selection and review process is presented in Figure 3-1. Summary scores of all 61 studies reviewed are presented in Appendix A.

Table 3-3: Number of citations obtained from electronic databases

Database	Number of records identified
EBSCOHOST (Africa-Wide; CINAHL, Psycinfo; PsycARTICLES)	320
PubMed (which includes Medline)	141
PsychiatryOnline	38
Science direct	240
Web of Science	1051
Scopus (which indexes EMBASE)	842
TOTAL	2674

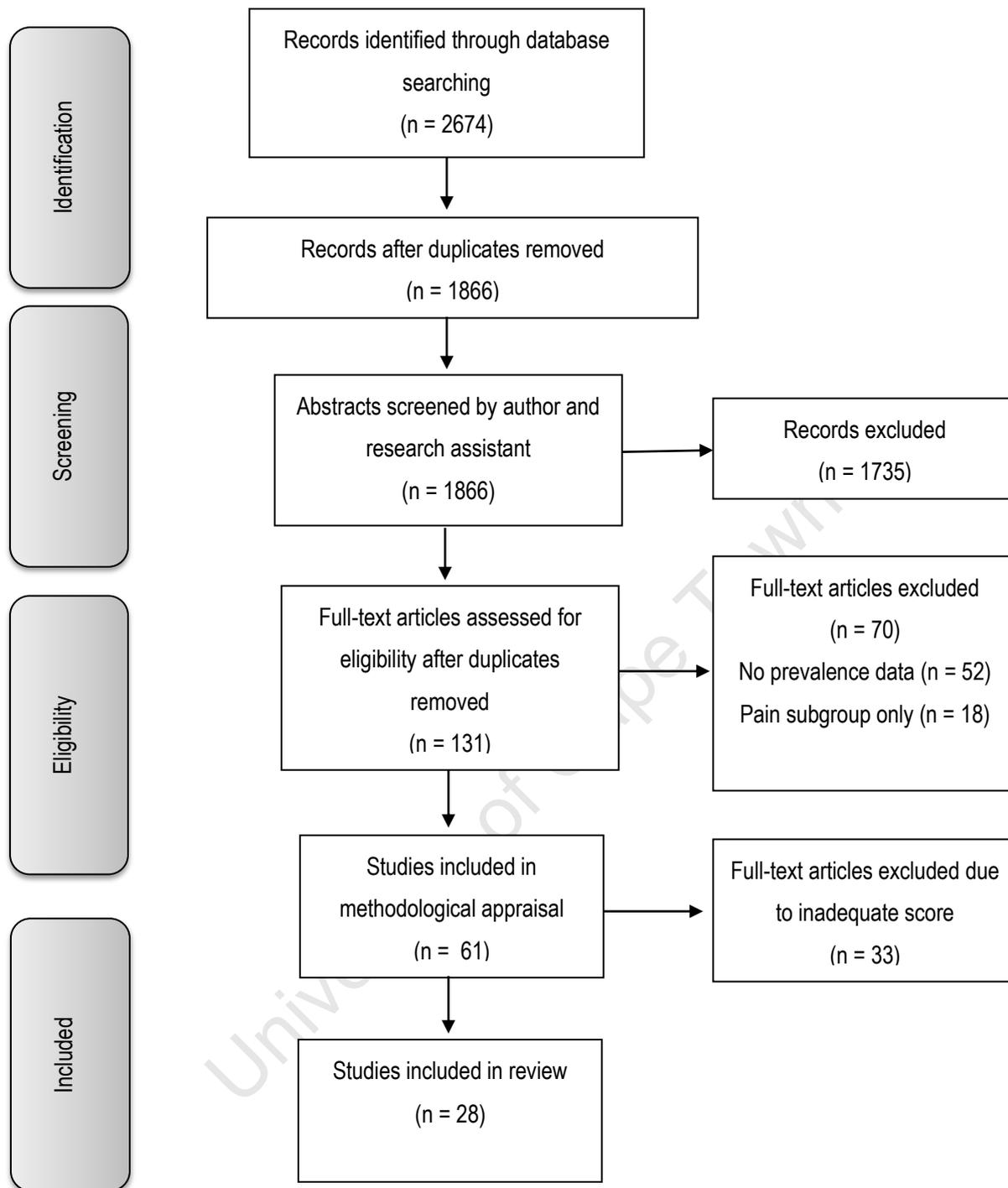


Figure 3-1: Flow diagram of the selection and review process

### 3.4.1 *Methodological appraisal of the studies*

All 61 articles selected for full text review were appraised using the 11-item methodological appraisal tool. The 28 studies with scores greater than or equal to the mean score (68%), were selected for review. A summary of the scores of the selected studies is presented in Table 3-4. The Mann-Whitney U test was used to compare the median prevalence rates in the studies not selected for review with the median rates of the studies selected for review, similarly the t-test was used to compare the mean rates between these studies. There was no significant difference between either the median or the mean prevalence rates (point prevalence, one week, two week and one month prevalence rates) of the studies selected for review and those not selected.

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Table 3-4: Scores of selected studies using 11-item methodological appraisal tool

Author (year) <sup>reference</sup>	1. Entire target population/randomly selected sample/sample stated to represent target population.	2. Non-responders.	3. Response rate.	4. Description of population.	5. Primary data on the prevalence of pain in PLWHA?	6. The same mode of data collection.	7. Validated questionnaire/interview/examination or at least tested for reproducibility or adequately described and standardized.	8. Data collected directly from the participant?	9. Precise description of what is meant by pain?	10. Further useful specification on pain?	11. Prevalence recall periods stated.	SCORE (%)
McCormack et al(1993) <sup>71</sup>	1	0	0	1	1	1	1	1	1	1	1	82
Eldridge et al (1994) <sup>72</sup>	1	1	0	1	1	1	1	0	0	1	1	73
Breitbart et al(1996) <sup>14</sup>	0	1	1	1	1	1	1	1	1	1	1	91
Breitbart et al (1997) <sup>73</sup>	0	0	0	1	1	1	1	1	1	1	1	73
Rosenfeld et al (1996) <sup>74</sup>	0	1	1	1	1	1	1	1	1	1	1	91
Larue et al (1997) <sup>6</sup>	1	1	0	1	1	1	1	1	1	1	1	91
Martin et al (1999) <sup>75</sup>	1	1	1	1	1	1	0	1	1	1	0	82
Frich & Borgbjerg (2000) <sup>76</sup>	1	1	1	1	1	1	0	1	0	1	0	73
Rotheram-Borus (2000) <sup>77</sup>	1	1	1	1	0	1	0	1	0	1	1	73
Brechtl et al (2001) <sup>78</sup>	1	1	1	1	0	1	1	1	1	0	1	82
Del Borgo et al (2001) <sup>79</sup>	1	1	1	1	1	1	1	1	1	1	1	100
Cowdery & Pesa (2002) <sup>80</sup>	1	0	1	1	0	1	1	1	0	1	1	73

Author (year) <sup>reference</sup>	1. Entire target population/randomly selected sample/sample stated to represent target population.	2. Non-responders.	3. Response rate.	4. Description of population.	5. Primary data on the prevalence of pain in PLWHA?	6. The same mode of data collection.	7. Validated questionnaire/interview/examination or at least tested for reproducibility or adequately described and standardized.	8. Data collected directly from the participant?	9. Precise description of what is meant by pain?	10. Further useful specification on pain?	11. Prevalence recall periods stated.	SCORE (%)
Lagana et al (2002) <sup>81</sup>	1	1	1	1	0	1	1	1	1	0	1	82
Dobalian et al (2004) <sup>82</sup>	1	1	1	1	1	1	1	1	0	1	1	91
Hughes et al (2004) <sup>83</sup>	1	0	0	1	0	1	1	1	1	1	1	73
Aires & Bammann (2005) <sup>84</sup>	1	0	0	1	1	1	1	1	1	1	1	82
Jelsma et al (2005) <sup>85</sup>	1	1	1	1	0	1	1	1	1	1	1	91
Hitchcock et al (2008) <sup>86</sup>	1	1	1	1	1	1	1	1	1	1	1	100
Lee et al (2009) <sup>87</sup>	1	1	0	1	0	1	1	1	0	1	1	73
Nair et al (2009) <sup>88</sup>	1	0	0	1	1	1	1	1	1	1	1	82
Richardson et al (2009) <sup>89</sup>	1	1	1	1	1	1	0	1	1	0	1	82
Aouizerat et al (2010) <sup>90</sup>	1	1	0	1	1	1	1	1	0	1	1	82
Hansen et al (2011) <sup>91</sup>	1	1	1	1	1	1	1	1	1	1	1	100
Miaskowski et al (2011) <sup>92</sup>	1	1	1	1	1	1	1	1	1	1	1	100
Mphahlele et al (2011) <sup>15</sup>	1	N/A	N/A	1	1	1	1	1	1	1	1	100

Author (year) <sup>reference</sup>	1. Entire target population/ran- domly selected sample/sample stated to represent target population.	2. Non- respon- ders.	3. Response rate.	4. Description of population.	5. Primary data on the prevalence of pain in PLWHA?	6. The same mode of data collecti on.	7. Validated questionnaire/i nterview/exami nation or at least tested for reproducibility or adequately described and standardized.	8. Data collected directly from the participant?	9. Precise descripti on of what is meant by pain?	10. Further useful specificat ion on pain?	11. Prevalence recall periods stated.	SCORE (%)
Narasimooloo et al (2011) <sup>93</sup>	1	0	0	1	1	1	1	1	1	1	1	82
Tran et al (2011) <sup>94</sup>	1	1	1	1	0	1	1	1	0	0	1	73
Wahab & Salami (2011) <sup>95</sup>	0	0	0	1	1	1	1	1	1	1	1	73

### 3.4.2 Description of the Studies

Descriptive data extracted from the 28 reviewed studies are presented in chronological order in Table 3-5. Three of the studies reviewed reported on the same data set in New York<sup>14 73 74</sup>, two studies reported on the same data set in Cape Town<sup>83 85</sup> and a further two studies reported on the same data set in San Francisco<sup>91 92</sup>. Data from the studies reporting on the same data sets were combined to prevent replication resulting in 24 samples reporting on a total of 6814 PLWHA.

None of the studies reviewed were published prior to 1993, 13 of the studies were published between 1993 and 2002; between 2003 and 2007 four studies were published and the remaining 11 studies were published between 2007 and 2011. In 2011 alone, six studies were published (Figure 3-2). The majority (19) of the studies were conducted in high income countries<sup>§</sup> with 14 from the USA; one from Canada; one from France; one from Denmark, one from Sweden and one from Italy. The remaining studies were conducted in the lower income countries of South Africa (five); Brazil (one) India (one); Vietnam (one) and Nigeria (one). The majority of the studies were conducted in urban settings with only one study reporting on a combination of rural and urban settings<sup>15</sup>. Sample sizes ranged from 50 participants in a single setting<sup>72 78</sup> to nationally representative samples of 400 in Vietnam<sup>94</sup> and 2267 all from the USA<sup>82</sup>. Only two of the studies reviewed included nationally representative samples of PLWHA<sup>82 94</sup>. The remainder of the studies used samples of convenience recruiting participants from health care centres.

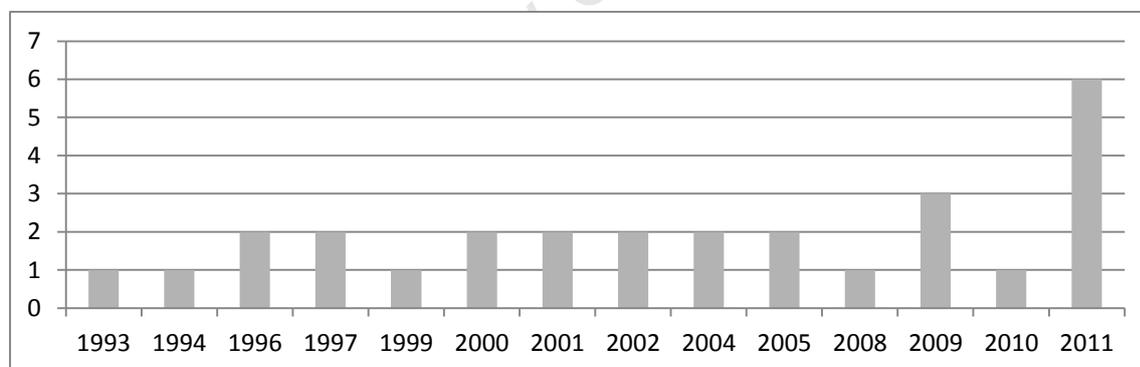


Figure 3-2: Number of studies included in the review per year

As per the inclusion criteria all the participants in the studies were either HIV+ or had been diagnosed with AIDS. Females made up 38% of the total sample reported on in the studies. Females made up less than 50% of the sample in 18 of the studies. The proportion of females in each sample is illustrated in Figure 3-3. Less than 25% of the sample was female in seven studies<sup>6 72 75 76 82 87 90</sup> and between 25 and 50% of the sample was female in 11 of the studies<sup>14 73 74 78 79 81 84 88 91 92 94</sup>.

§§ According to the World Bank, high income countries have a per capita GNI of US\$12476 or more.

In four studies females made up between 50 and 75% of the sample<sup>83 85 93 95</sup> and in a further four studies females made up more than 75% of the sample<sup>15 77 80 89</sup>. Two studies did not report on the representation of males and females in the samples<sup>71 86</sup>.

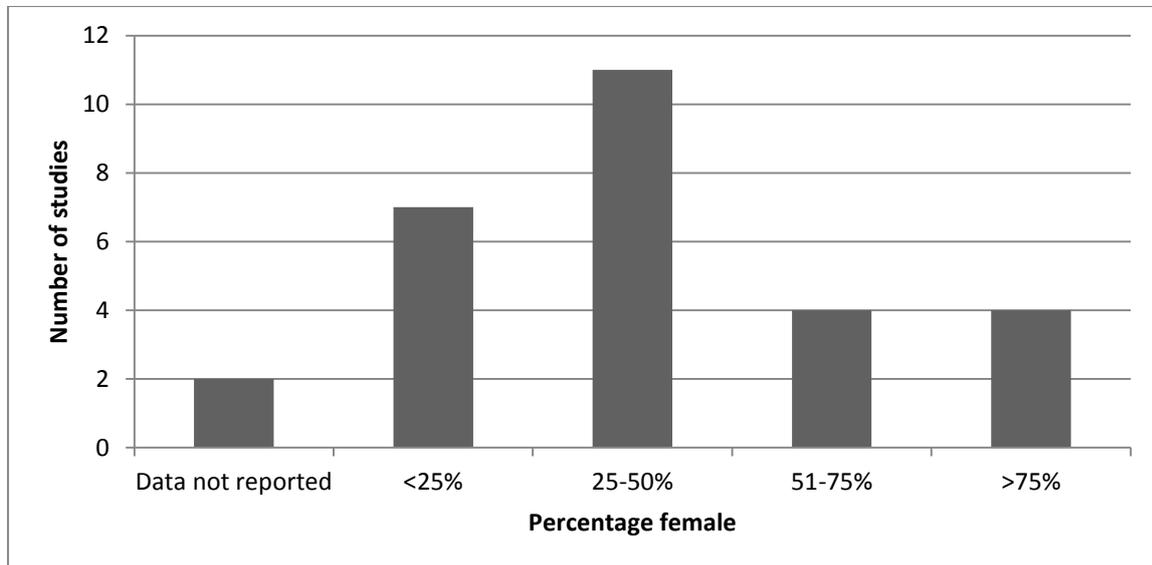


Figure 3-3: Proportion of females in the samples of the selected studies

Table 3-5: Summary of reviewed studies

Author (year) reference	Setting	Population (sample size)	Age (y) (mean $\pm$ SD or range)	Female (%)	Ethnicity (%)	Disease Stage (%) and/or CD4+ count (cells/mm <sup>3</sup> ) (mean $\pm$ SD) or [median (range)] or CD4+ < 200 (%)	Time since diagnosis (months)	On HAART (%)	Measurement Instrument	Pain prevalence (%) (period)
McCormack et al (1993) <sup>71</sup>	Vancouver, Canada	Ambulatory HIV+ patients of an infectious diseases unit (148)	40.4	Missing	Missing	AIDS [173]	53	Missing	WBPQ	55 (1 month)
Eldridge et al (1994) <sup>72</sup>	Boston, USA	Terminal AIDS patients in residential hospice (50)	37.6	25	Black (16) Hispanic (14) White (38) Other (4) Unknown (28)	AIDS	Missing	Missing	Interview	40 (point prevalence)
Breitbart et al (1996) <sup>14</sup> and Rosenfeld et al (1996) <sup>74*</sup>	New York, USA	Ambulatory AIDS patients (438)	38.83	36.1	Black (37) Hispanic (22.9) White (38.1) Other (2.3)	AIDS [150 (0 - 1929)]	52.8	53.9	BPI	62.6 (2 weeks)

Author (year) reference	Setting	Population (sample size)	Age (y) (mean ± SD or range)	Female (%)	Ethnicity (%)	Disease Stage (%) and/or CD4+ count (cells/mm <sup>3</sup> ) (mean ± SD) or [median (range)] or CD4+ < 200 (%)	Time since diagnosis (months)	On HAART (%)	Measurement Instrument	Pain prevalence (%) (period)
Breitbart et al (1997) <sup>73*</sup>	New York, USA	Ambulatory AIDS patients (516)	38.96 ± 9.7 (IDU) 38.13 ± 7.9 (non-IDU)	49.5 (IDU) 39 (non-IDU)	Black (39.6; 39.4) Hispanic (27.4; 17.5) White (31.1; 39.8) Other (1.9; 3.3) (IDU; non-IDU)	AIDS CD4+ < 200 (31.1; 71.1) (IDU; non-IDU)	51.05 ± 30.6 (IDU) 54.51 ± 33.9 (non-IDU)	Missing	BPI	63.6 (2 weeks) [67 (IDU); 59 (non-IDU)]
Larue et al (1997) <sup>6</sup>	13 cities across France	HIV+ IP and OP (290)	33 (21 - 66)	22	Missing	Asymptomatic (3; 3; 20) Pathologic (5, 16, 23) AIDS (80; 75; 50) IP; DP; OP	Missing	Missing	BPI (French)	62; 53; 30 IP; DP; OP (1 week)
Martin et al (1999) <sup>75</sup>	Stockholm, Sweden	HIV+ OP attending Dept. of Infectious Diseases (255)	F 38; M 40	22	Missing	Asymptomatic 53; Symptomatic 32; AIDS 15	Missing	Missing	Questionnaire	85; 71 IDU, non-IDU
Frich & Borgbjerg (2000) <sup>76</sup>	Copenhagen, Denmark	AIDS patients at a Dept. of Infectious Diseases (95)	40 ± 9	12.6	Danish (87) Scandinavian (4) African (5) Other (3)	AIDS	19.7 ± 18.7 (pain) 14.8 ± 13.9 (no pain)	50	Interview	74 (point prevalence)

Author (year) reference	Setting	Population (sample size)	Age (y) (mean $\pm$ SD or range)	Female (%)	Ethnicity (%)	Disease Stage (%) and/or CD4+ count (cells/mm <sup>3</sup> ) (mean $\pm$ SD) or [median (range)] or CD4+ < 200 (%)	Time since diagnosis (months)	On HAART (%)	Measurement Instrument	Pain prevalence (%) (period)
Rotheram- Borus et al (2000) <sup>77</sup>	New York, USA	Low-income advanced HIV or AIDS (151)	37.6 $\pm$ 5.2	86.8	Black (39) Hispanic (41) White (9) Other (1)	32% AIDS CD4+ < 200 (61)	15 $\pm$ 22 (AIDS diagnosis)	Missing	Missing	83 (3 months)
Brechtel et al (2001) <sup>78</sup>	New York, USA	AIDS patients at discreet nursing unit (50)	34	33	Black (44) Hispanic (23) White (9) Unknown/mixed (24)	AIDS CD4+ [35(0-265)]	Missing	Naïve	BPI	62 (2 weeks)
Del Borgo et al (2001) <sup>79</sup>	Rome, Italy	HIV+ admitted to ward or day treatment centre (153)	36 $\pm$ 6.5	28.1	Missing	Groups A and B (23.5) Group C (76.5)	Missing	34	IPQ (Italian MPQ)	60.80 (point prevalence)
Cowdery & Pesa (2002) <sup>80</sup>	South-eastern USA	Women receiving routine HIV treatment in a public clinic (82)	37.5 $\pm$ 9.3	100	Black (67.1) White (32.9)	A (42.2) B (28.2) C (28.2) (402.4 $\pm$ 363.6)	36.9 $\pm$ 29.4	Missing	MOS-SF-20	63 (1 month)

Author (year) reference	Setting	Population (sample size)	Age (y) (mean $\pm$ SD or range)	Female (%)	Ethnicity (%)	Disease Stage (%) and/or CD4+ count (cells/mm <sup>3</sup> ) (mean $\pm$ SD) or [median (range)] or CD4+ < 200 (%)	Time since diagnosis (months)	On HAART (%)	Measurement Instrument	Pain prevalence (%) (period)
Lagana et al (2002) <sup>81</sup>	Northern California, USA	HIV+ OPs recruited for psychotherapy intervention study (120)	40 $\pm$ 7.5	42.5	Black (31.7) Hispanic (10.8) White (57.5) Native American (7.5) Other (10)	Missing	74.7 $\pm$ 42.5	75	Rating of chronic pain	48.3 (chronic pain > 6 months)
Dobalian et al (2004) <sup>82</sup>	USA	HIV+ OP nationally representative sample (2267)	39	22.4	Black (32.2) Hispanic (15) White (49.3) Other (3.5)	AIDS (48.3) CD4+ < 200 (53.8)	Missing	Missing	SF-36	67 (1 month)
Hughes et al (2004) <sup>83+</sup>	Khayelitsha, Cape Town, South Africa	HIV+ outpatients initiating HAART (123)	33.8 $\pm$ 7.8	65	Missing	AIDS (100) CD4+ < 200 (100)	Missing	Naive	EQ-5D	69.10 (point prevalence)
Aires & Bammann (2005) <sup>84</sup>	Sao Paulo, Brazil	HIV+ IP on admission (197)	34	26	Missing	HIV+	Missing	Missing	Modified WBPQ	54.3 (2 weeks)

Author (year) reference	Setting	Population (sample size)	Age (y) (mean ± SD or range)	Female (%)	Ethnicity (%)	Disease Stage (%) and/or CD4+ count (cells/mm <sup>3</sup> ) (mean ± SD) or [median (range)] or CD4+ < 200 (%)	Time since diagnosis (months)	On HAART (%)	Measurement Instrument	Pain prevalence (%) (period)
Jelsma et al (2005) <sup>85+</sup>	Khayelitsha, Cape Town, South Africa	HIV+ OP on HAART (117)	Missing	74.5	Missing	AIDS	Missing	100%	EQ-5D	54.9 (point prevalence at 1 month post initiation of HAART) 46.4 (at 3 months) 39.8 (6 months) 26.5 (1 y)
Hitchcock et al (2008) <sup>86</sup>	Pretoria, South Africa	AIDS pt's initiating HAART (354)	36.3 ± 8.6	Missing	Missing	AIDS (111 ± 70.8)	Missing	Naive	Missing	62.1 (2 weeks)

Author (year) reference	Setting	Population (sample size)	Age (y) (mean ± SD or range)	Female (%)	Ethnicity (%)	Disease Stage (%) and/or CD4+ count (cells/mm <sup>3</sup> ) (mean ± SD) or [median (range)] or CD4+ < 200 (%)	Time since diagnosis (months)	On HAART (%)	Measurement Instrument	Pain prevalence (%) (period)
Lee et al (2009) <sup>87</sup>	San Francisco, USA,	Living with HIV/AIDS for minimum of 3 months, attending HIV Clinics and Community sites (317)	45.1 ± 8.3; 45.9 ± 8.2; 43.3 ± 9.1 (M; F; Trans)	24.6	Black (28; 61; 61) Hispanic (11; 8; 13) White (50; 23;13) Mixed (8; 4; 9) Other (3; 4; 4) (M;F;Trans)	AIDS 56; 46; 35 CD4+ (462 ± 275); (439 ± 246); (380 ± 232) (M; F; Trans)	12.4 ± 7.0; 11.1 ± 6.5; 11.5± 7.4 (M; F; Trans)	71	MSAS	55 (1 week)
Nair et al (2009) <sup>88</sup>	South India	IP and OP at HIV care centres, 90% ambulatory (42 IP, 98 OP)	18-68	41	Missing	Stage I (35); Stage II (11.5); Stage III (25); Stage IV (27)	Missing	60 (those with pain)	BPI	66.7 (IP) 24.5 (OP) (1 week)

Author (year) reference	Setting	Population (sample size)	Age (y) (mean $\pm$ SD or range)	Female (%)	Ethnicity (%)	Disease Stage (%) and/or CD4+ count (cells/mm <sup>3</sup> ) (mean $\pm$ SD) or [median (range)] or CD4+ < 200 (%)	Time since diagnosis (months)	On HAART (%)	Measurement Instrument	Pain prevalence (%) (period)
Richardson et al (2009) <sup>89</sup>	New York, Chicago, Washington DC, LA; USA	Women living with HIV (104+66+68+1 01=339)	62.8% < 39	100	Black (53.7) Hispanic (29.5) White (16.5)	Asymptomatic (35) CD4+ < 200 (57.5)	Missing	60	Missing	83.5 (6 months)
Aouizerat et al (2010) <sup>90</sup>	San Francisco, USA	HIV+ OP (350)	45.3	24.6	Black (39) Hispanic (10) White (41) Other (10)	AIDS (52); (449 $\pm$ 265)	12.1 $\pm$ 7	71	MSAS	55 (1 week)
Hansen et al (2011) <sup>91</sup> and Miaskowski et al (2011) <sup>92#</sup>	San Francisco, USA	Indigent PLWHA (296)	49.5 $\pm$ 7.5 (29.3% F)	28.1	Black (41.9) White (38.1) Other (20)	HIV+ CD4+ < 200 (54.8)	Missing	74.8	BPI	91.2 (1 week)

Author (year) reference	Setting	Population (sample size)	Age (y) (mean ± SD or range)	Female (%)	Ethnicity (%)	Disease Stage (%) and/or CD4+ count (cells/mm <sup>3</sup> ) (mean ± SD) or [median (range)] or CD4+ < 200 (%)	Time since diagnosis (months)	On HAART (%)	Measurement Instrument	Pain prevalence (%) (period)
Mphahlele et al (2011) <sup>15</sup>	Urban and rural South Africa	HIV+ OP (Rural 125; Urban 396)	36 ± 9 (rural) 36 ± 8 (urban)	79 (rural) 75 (urban)	Black (100) (rural) Black (93) (urban)	[199 (120 - 346)] (rural) [200 (99 - 309)] (urban)	Missing	53 (rural) 68 (urban)	WBPQ	72 (rural) 66 (urban) (point prevalence) 67 (rural) 77 (urban) (1 month)
Narasimool oo et al (2011) <sup>93</sup>	Kwazulu-Natal South Africa	HIV+ IP Urban district hospital (100)	21-30 (34%) 31-40 (47%) 41-50 (16%) > 50y (3%)	66	Missing	Stage II (3) Stage III (29) Stage IV (68) CD4+ < 200 (70)	42% HIV+ < 6 months	34	BPI	91 (point prevalence)
Tran et al (2011) <sup>94</sup>	Vietnam	Nationally representative sample of adults LWHA (400)	30 (27 – 33)	37.3	Missing	Asymptomatic (43.8)	60 (95%CI 56.4 – 63.6)	56.25	EQ-5D	15.5 (point prevalence) [19.1 (on HAART) 10.9 (not on HAART)]

Author (year) reference	Setting	Population (sample size)	Age (y) (mean ± SD or range)	Female (%)	Ethnicity (%)	Disease Stage (%) and/or CD4+ count (cells/mm <sup>3</sup> ) (mean ± SD) or [median (range)] or CD4+ < 200 (%)	Time since diagnosis (months)	On HAART (%)	Measurement Instrument	Pain prevalence (%) (period)
Wahab & Salami (2011) <sup>95</sup>	Ilorin, Nigeria	PLWHA attending OP clinic of the University Hospital (79)	37.1 ± 8.6	59.5	Missing	Stage I (43) Stage II (35.4) Stage III (17.7) Stage IV (3.8) (234.9 ± 218.3)	28.5 ± 25.3	Missing	Modified BPI	27.8 (2 weeks)

\*same sample; +same sample; # same sample; OP = outpatients; IP = inpatients; M = male; F = female; Trans = transgender; IDU = intravenous drug user

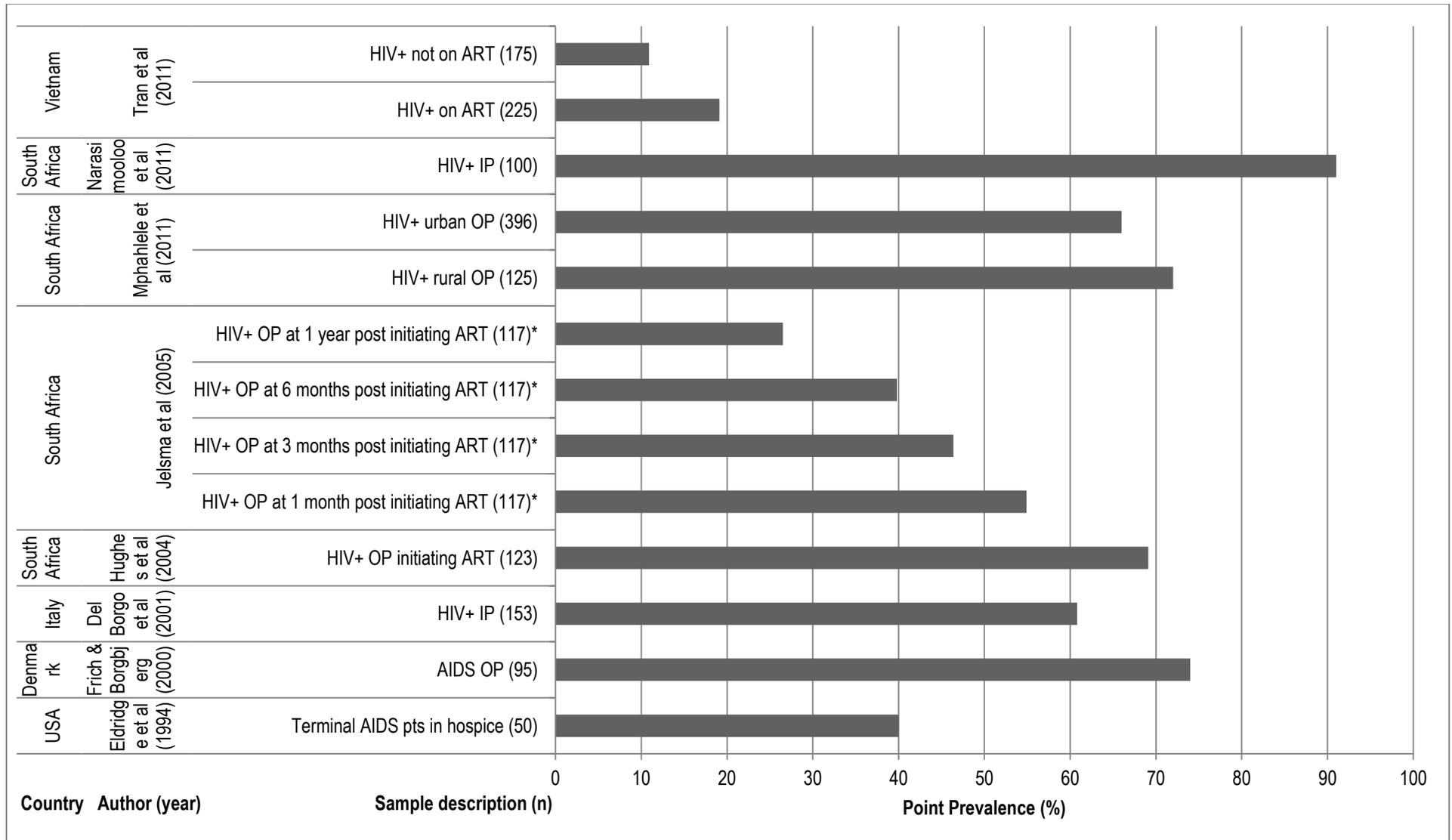
### 3.4.3 Prevalence of Pain

The studies used a range of measurement instruments to record pain. In 20 of the studies, pain as a symptom was clearly defined either in the study or in the measurement instrument used. Further information on pain was reported in 24 of the studies and pain prevalence periods were reported in 26 of the studies. The most commonly used instrument, the well validated Brief Pain Inventory (BPI), was used in ten studies<sup>6 14 73 74 78 88 91-93 95</sup>. The precursor of the BPI, the comparable Wisconsin Brief Pain Inventory was used in three studies<sup>15 71 84</sup>. Three studies used the health related quality of life measure, the EQ-5D, which includes a specific question on pain<sup>83 85 94</sup> and two studies used the Memorial Symptom Assessment Scale<sup>87 90</sup>. Validated interviews were used in two of the studies<sup>72 76</sup> and one study each used the SF-36<sup>82</sup>, the MOS-SF20<sup>80</sup> and the Italian version of the McGill Pain Questionnaire<sup>79</sup>. Five studies used self-developed instruments.

The pain recall periods ranged from point-prevalence to six-months. One study did not report a recall period<sup>75</sup>. Summaries of the reported prevalence rates over different recall periods will now be presented.

#### 3.4.3.1 Point prevalence of pain

The eight studies reporting point prevalence data had a combined sample of 1559 participants<sup>15 72 76 79 83 85 93 94</sup>. There was a large range in the reported point prevalence of pain and in the instruments used to record point prevalence (Figure 3-4). Instruments included the BPI<sup>93</sup>, the WBPQ<sup>15</sup>, the EQ-5D<sup>83 85 94</sup>, the Italian version of the McGill Pain Questionnaire<sup>79</sup> and structured interviews<sup>72 76</sup>. Point prevalence ranged from 10.9% in a Vietnamese community based sample<sup>94</sup> to 91% in an inpatient sample from an urban hospital in KwaZulu-Natal, South Africa<sup>93</sup>. Data from studies on the same population was managed to avoid duplication. The median point prevalence of pain was 54.9% (range 11 – 91%) and the weighted point prevalence of pain calculated from the pooled data (1559 participants) of the eight studies was 53.62% (95% CI 51.14 – 56.09).

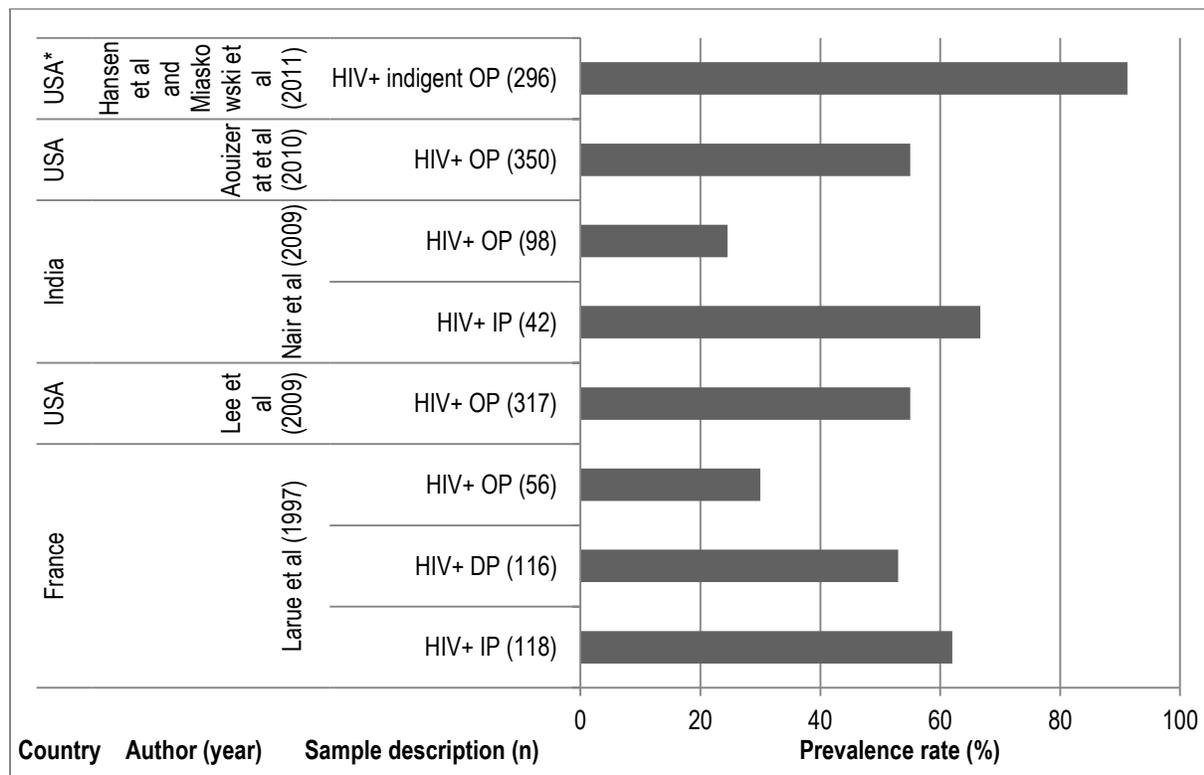


\* Same cohort followed for one year; OP = outpatients; IP = inpatients

Figure 3-4: Summary of point prevalence rates (n = 1559)

### 3.4.3.2 One week recall period prevalence of pain

Six studies reported the prevalence of pain for a one week recall period<sup>6 87 88 90-92</sup>; however, two of these studies reported on the same sample<sup>91 92</sup>, effectively resulting in five samples with prevalence of pain for a one week recall period with a sample of 1393 PLWHA. Four studies used the BPI<sup>6 88 91 92</sup> while the remaining two studies used the MSAS<sup>87 90</sup>. The prevalence rates ranged from 30% in the outpatient sub-group of a study conducted in France<sup>6</sup>, to 91.2% in the sample from San Francisco, USA<sup>91 92</sup> (Figure 3-5). The median prevalence of pain for a one week recall period was 55% (25 – 91%). The prevalence rate for a one week recall period calculated from the pooled data (1393 PLWHA) was 60.3% (95% CI 58 – 63).

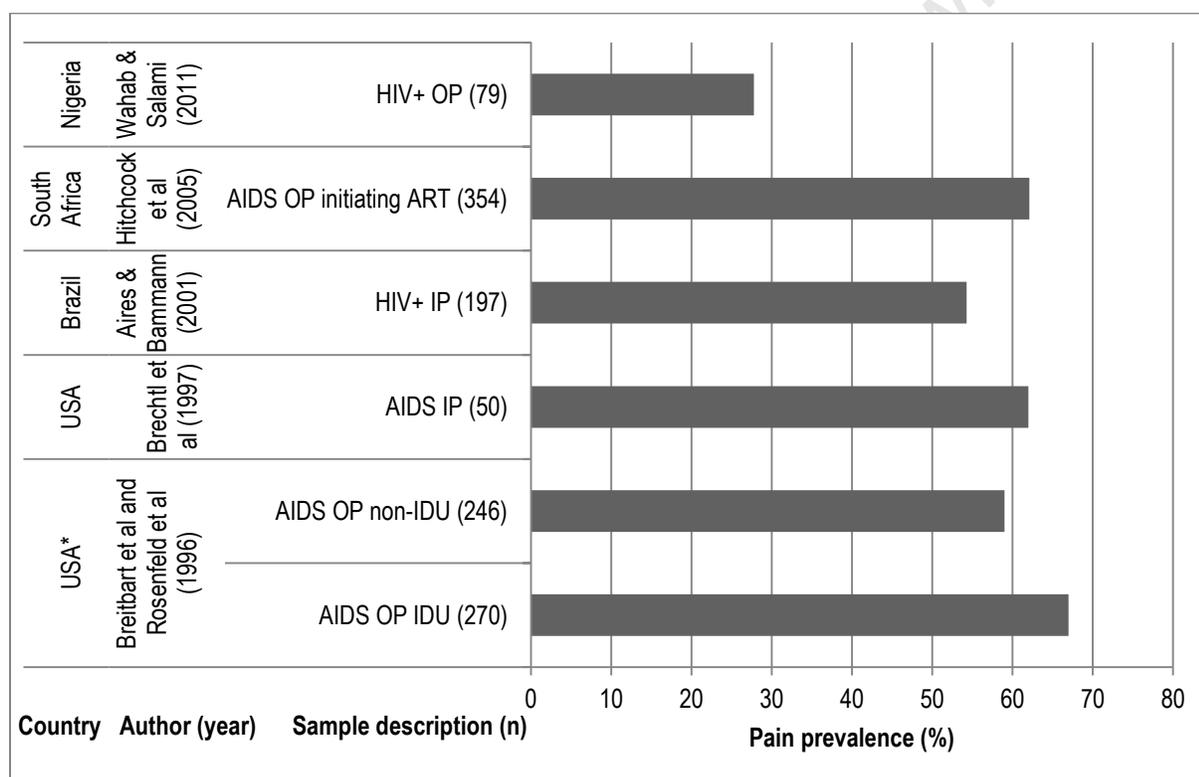


\*Two studies reporting on a single sample; IP = inpatient; OP = outpatient; DP = day patient

Figure 3-5: Summary of pain prevalence rates for a one week recall period (n = 1393)

### 3.4.3.3 Two week recall period prevalence of pain

Seven studies reported on the prevalence of pain using a two week recall period<sup>14 73 74 78 84 86 95</sup>; however, three of these studies reported on the same sample<sup>14 73 74</sup> resulting in five samples with prevalence rates for a two week recall period with 842 participants (Figure 3-6) (Two of the three studies used the same data set<sup>14 74</sup>, the third reported on a subset of the data and was excluded). One study used the precursor to the BPI, the modified WBQP<sup>84</sup> while the remaining studies all used the BPI. The prevalence rates ranged from 27.8% in a group of outpatients attending a clinic at the University Hospital in Ilorin, Nigeria<sup>95</sup> to 62.6% in a sample of ambulatory outpatients with AIDS living in New York, USA<sup>14 73 74</sup>. The median prevalence rate for a two week recall period was 62% (28 – 67%). The mean prevalence rate for a two week recall period calculated from the pooled data of these studies for the 842 participants was 58% (95% CI 55 – 61).

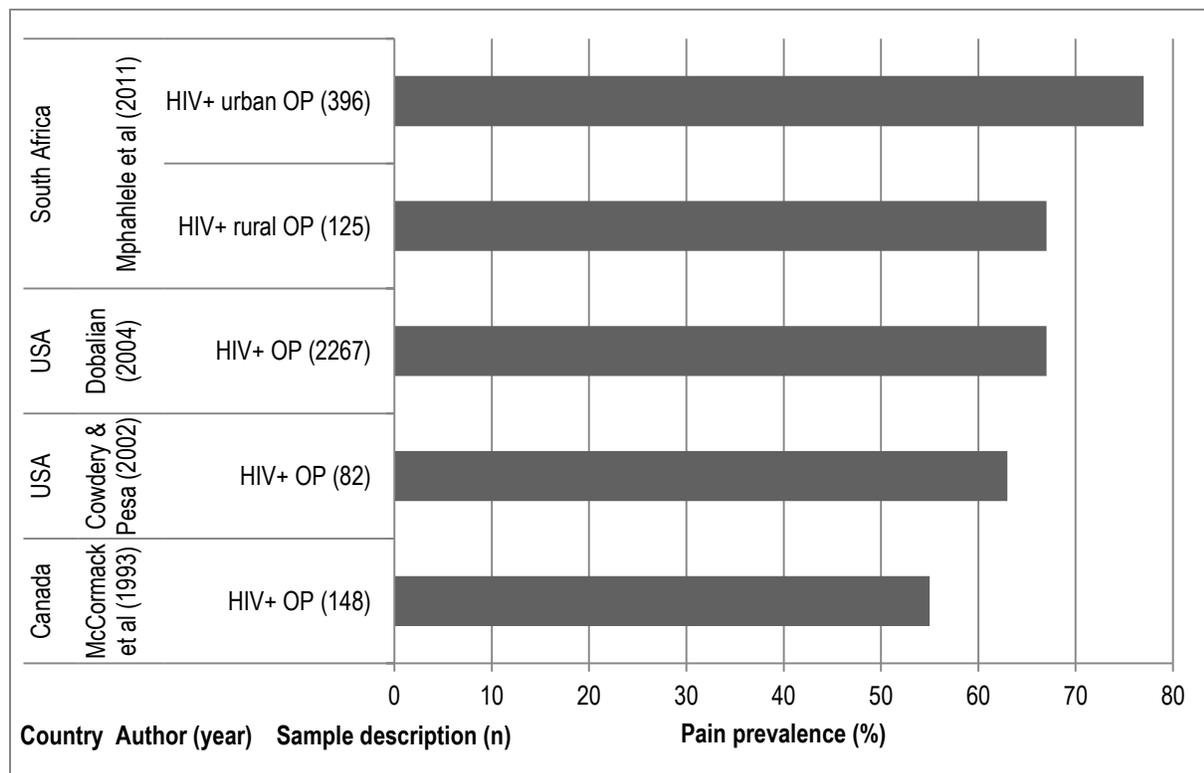


\*Two studies reported on the same sample; IP = inpatient; OP = outpatient; DP = day patient; IDU = intravenous drug use

Figure 3-6: Summary of pain prevalence rates for a two week recall period (n = 842)

#### 3.4.3.4 One month recall period prevalence of pain

Four studies with 3018 participants reported the prevalence of pain for a one month recall period<sup>15 71 80 82</sup>. Two of the studies used the WBPQ<sup>15 71</sup>, one used the SF-36<sup>82</sup> and one used the MOS-SF20<sup>80</sup>. The prevalence of pain ranged from 55% in the 1993 study conducted in Vancouver on ambulatory HIV+ outpatients; to 77% in a sample of urban South Africans living with HIV receiving treatment at an ARV clinic (Figure 3-7). The median prevalence rate using a one month recall period was 67% (55 – 77%). The mean prevalence rate for a one month recall period calculated from the pooled data of the 3018 participants was 67.6% (95% CI 66 – 69).



OP = outpatient

Figure 3-7: Summary of pain prevalence using a one month recall period (n = 3018)

#### 3.4.3.5 Three to six month recall period prevalence of pain

One study reported on the prevalence of pain using a three month recall period in a sample of 151 low-income PLWHA<sup>77</sup>. Using a self-developed questionnaire, a pain prevalence rate of 83% was reported.

Two studies reported on the prevalence of pain over using a six month recall period<sup>81 89</sup>. The study by Richardson and colleagues<sup>89</sup> identified the prevalence of pain using a six month recall period while that of Lagana et al<sup>81</sup> focused on the prevalence of chronic pain, defined as “constant pain for entire six months”. The prevalence of pain within a six-month period was reported as 83.5%<sup>89</sup>, while the second study reported a lower prevalence for chronic pain of 48.3%<sup>81</sup>.

### 3.4.4 *Factors contributing to pain*

Factors which contributed to the presence of pain in different samples were explored in several of the studies. For the purposes of the review, the factors explored were categorised as demographic factors, stage of disease, pharmacological management, intravenous drug use and psychological factors.

#### 3.4.4.1 Demographic factors

Six studies reported on the contribution of demographic variables to the presence of pain<sup>14 82 86 89 90 92</sup>. Two of the studies reported that women had a higher prevalence of pain than men<sup>14 92</sup> with a further study identifying female IDU's as having a higher prevalence of pain than male IDU's<sup>82</sup>. Conversely, Hitchcock and colleagues<sup>86</sup> found a higher prevalence of pain in males in their sample from Tshwane, South Africa. One study, reporting on female participants with CD4+ < 200cells/microL, found no relationships between any demographic variables and pain prevalence<sup>89</sup>.

With regard to ethnic groups, three studies with diverse ethnic groups reported a higher prevalence of pain in black participants<sup>82 90</sup> and a further study reported a higher prevalence of pain in non-Caucasian groups<sup>14</sup>. Two studies found that lower levels of education increased pain prevalence<sup>82 92</sup>.

#### 3.4.4.2 Stage of disease

The relationship between stage of disease and the presence of pain was explored in eight of the studies reviewed<sup>14 75 79 82 88-90 95</sup>. Two of the studies reported higher pain prevalence in participants with lower CD4+ counts on regression analysis<sup>89 90</sup> and a third reported a correlation between number of pain sites and CD4+ count<sup>75</sup>. Three of the studies reported a higher prevalence of pain in participants with more advanced disease (Stage III or IV or CDC category C)<sup>75 82 88</sup>. However, three other studies reported no differences between the prevalence of pain in different stages of the disease or according to CD4+ counts<sup>14 79 95</sup>.

#### 3.4.4.3 Pharmacological management

Two studies reported on the relationship between pharmacological treatment and the prevalence of pain<sup>14 89</sup>. These three studies report conflicting results with Breitbart et al<sup>14</sup> reporting that the ambulatory AIDS participants receiving ART in their study had a lower prevalence of pain than those not receiving ART. However, Richardson and colleagues<sup>89</sup> more recent work on women with AIDs found no difference in prevalence rates between those receiving and not receiving ART.

#### 3.4.4.4 Intravenous drug use

The relationship between a history of intravenous drug use (IDU) and pain prevalence was reported in six studies<sup>14 75 79 82 89 91</sup>. The earliest of these studies from Breitbart and colleagues<sup>14</sup> reported no differences in the prevalence of pain between participants with a history of IDU and non-IDU. However, the subsequent studies all report significantly higher rates of pain (prevalence and severity) in the IDU group<sup>75 79 82 89 91</sup>. In addition, sub-analysis in two studies revealed a clear relationship between the prevalence of pain and stage of disease in the non-IDU groups, which was not present in the IDU group<sup>75 79</sup>.

#### 3.4.4.5 Psychological factors

Five of the studies reviewed reported on psychological factors as contributors to pain<sup>74 77 81 89 92</sup>. All of these studies noted an association between the presence of psychological distress or illness and pain. Both greater levels of psychological distress and lower levels of emotional control were associated with greater levels of pain<sup>15,19,23</sup>. Two of the studies reported that pain severity was associated with worse depression scores<sup>89 92</sup> and one noted that pain was associated with lower levels of perceived social support<sup>74</sup>.

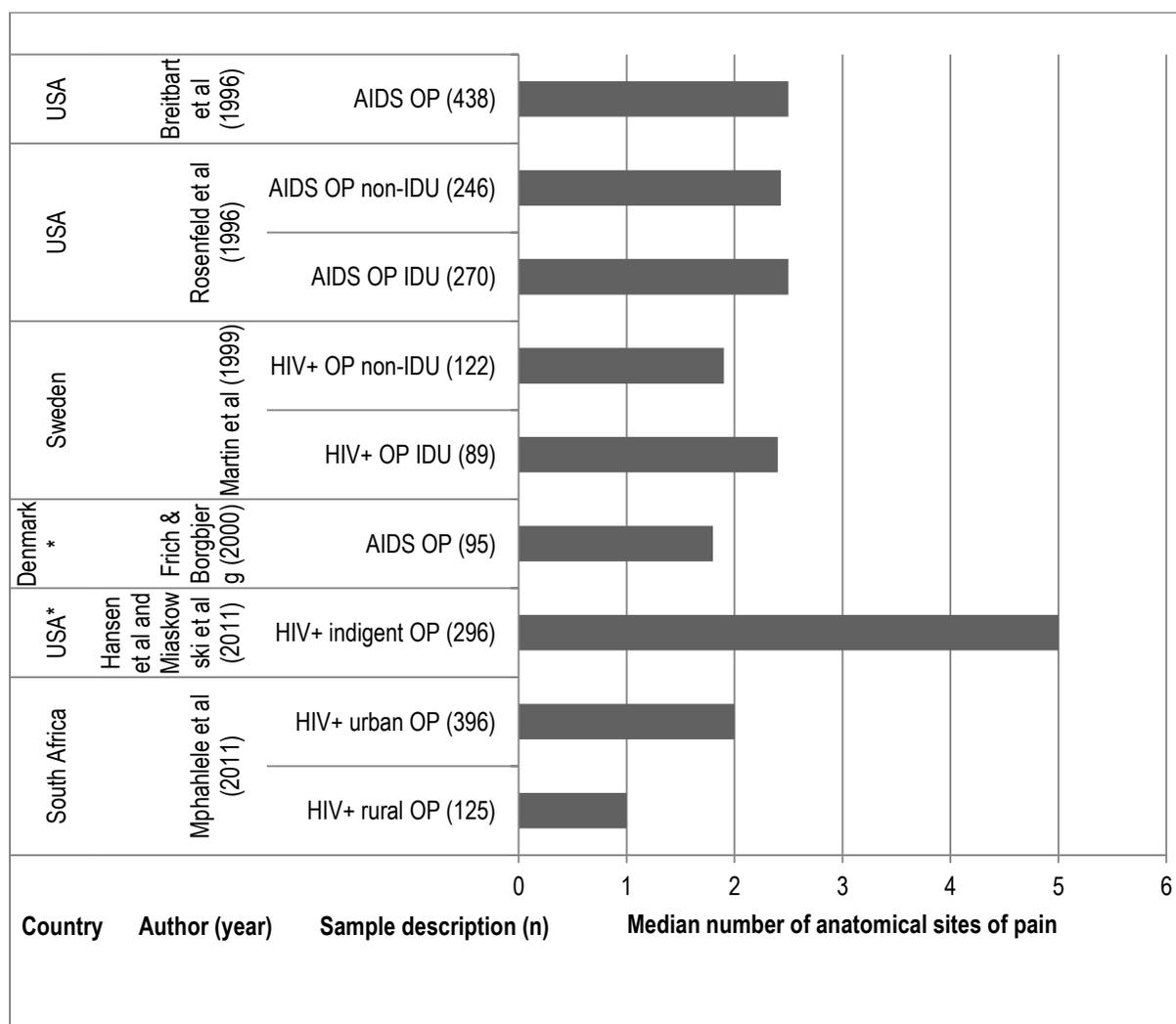
Information on the characteristics of the pain experienced by PLWHA including the severity and sites of pain reported in the studies reviewed will now be presented.

### 3.4.5 *Characteristics of Pain*

Depending on the measurement instrument used, some studies reported on the anatomical sites of reported pain as well as on the prevalence of mild, moderate and severe pain. A summary of this data is presented here.

### 3.4.5.1 Pain sites

Of the 28 studies reviewed, 14 reported on anatomical sites of pain in 2077 participants. The number of different anatomical sites was recorded in five of the studies<sup>14 15 73 75 76</sup> while 12 of the studies reported prevalence of pain in specific anatomical sites<sup>6 15 71 72 75-77 79 84 86 88 95</sup>. The number of anatomical sites reported ranged from a median of 1 (1 – 2) in the rural South African sample of the study by Mphahlele and colleagues<sup>15</sup> to a median of 2.5 (1 – 5) in the sample from New York reported on by Breitbart and colleagues<sup>14 73</sup> (Figure 3-8). The relative frequencies of pain in different anatomical sites varied across these twelve studies (Figure 3-9). All 12 of the studies listed the lower limbs as a specific site of pain; the next most frequently reported site of pain was the head (10).



\* Mean number of sites of pain; OP = outpatient; IDU = intravenous drug use

Figure 3-8: Summary of median number of anatomical sites reported (n = 2077)

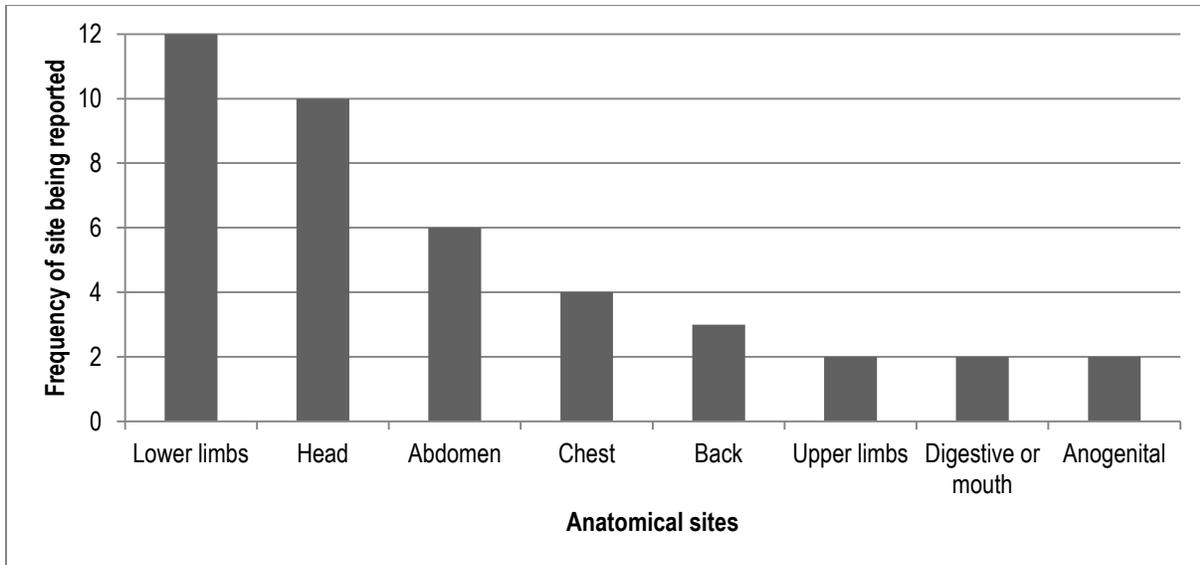


Figure 3-9: Frequency of reported sites of pain

### 3.4.5.2 Pain Severity

Eighteen of the studies reviewed reported on the prevalence of pain according to severity as summarised in Table 3-6. The distribution of pain severity (mild, moderate and severe pain) varied across the studies.

Table 3-6: Summary of studies reporting pain severity

Author (year) <sup>ref</sup>	Setting	Population (sample size)	Pain prevalence (%) (period)	Mild pain (%)	Moderate pain (%)	Severe pain (%)
Eldridge et al (1994) <sup>72</sup>	Boston, USA	Terminal AIDS patients in residential hospice (50)	40 (point prevalence)	Missing	Missing	38
Breitbart et al and Rosenfeld et al (1996) <sup>14 74</sup>	New York, USA	Ambulatory AIDS patients (438)	62.6 (2 weeks)	19	64	17
Larue et al (1997) <sup>6</sup>	13 cities across France	HIV+ IP and OP (290)	62; 53; 30 (IP; DP; OP) (1 week)	Missing	Missing	16 (OP) 51 (IP)
Frich & Borgbjerg (2000) <sup>76</sup>	Copenhagen, Denmark	AIDS patients at a Dept. of Infectious Diseases (95)	74 (point prevalence)	Missing	48	Missing
Del Borgo et al (2001) <sup>79</sup>	Rome, Italy	HIV+ admitted to ward or day treatment centre (153)	60.80 (point prevalence)	11.5	32.8	32.1 (distressing) 15.2 (exhausting) 8.4 (unbearable)
Cowdery & Pesa (2002) <sup>80</sup>	South-eastern USA	Women receiving routine HIV treatment in a public clinic (82)	63 (1 month)	Missing	Missing	15.9
Dobalian et al (2004) <sup>82</sup>	USA	HIV+ OP nationally representative sample (2267)	67 (1 month)	45.1	46.8	7.1
Hughes et al (2004) <sup>83</sup>	Khayelitsha, Cape Town, South Africa	HIV+ outpatients initiating HAART (123)	69.10 (point prevalence)	Missing	62	8.1

Author (year) <sup>ref</sup>	Setting	Population (sample size)	Pain prevalence (%) (period)	Mild pain (%)	Moderate pain (%)	Severe pain (%)
Aires & Bammann (2005) <sup>84</sup>	Sao Paulo, Brazil	HIV+ IP on admission (197)	54.3 (2 weeks)	12.2	27.1	60.7
Jelsma et al (2005) <sup>85</sup>	Khayelitsha, Cape Town, South Africa	HIV+ OP on HAART (117)	54.9 (1 month) 46.4 (3 months) 39.8 (6 months) 26.5 (1 y) (point prevalence)	Missing	48 (1 month) 44.3 (3 months) 37.8 (6 months) (1 y)	6.9 (1 month) 2.1 (3 months) 2.0 (6 months) 2.4 (1 y)
Lee et al (2009) <sup>87</sup>	San Francisco, USA,	PLWHA for minimum of 3 months, attending HIV Community Clinics (317)	55 (1 week)	Missing	Missing	34
Aouizerat et al (2010) <sup>90</sup>	San Francisco, USA	HIV+ OP (350)	55 (1 week)	Missing	Missing	82
Hansen et al and Miaskowski et al (2011) <sup>91 92</sup>	San Francisco, USA	Indigent PLWHA (296)	91.2 (1 week)	8.1	91.8 (moderate to severe)	Missing
Mphahlele et al (2011) <sup>15</sup>	Urban and rural South Africa	HIV+ OP (Rural 125; Urban 396)	72 (rural) 66 (urban) (point prevalence)	Missing	60 (rural) 50 (urban) (moderate to severe)	Missing
Narasimooloo et al (2011) <sup>93</sup>	Kwazulu-Natal South Africa	HIV+ IP Urban district hospital (100)	91 (point prevalence)	8	23	60
Wahab & Salami (2011) <sup>95</sup>	Ilorin, Nigeria	PLWHA attending OP clinic of the University Hospital (79)	27.8 (2 weeks)	70	10	15

*IP = inpatient; OP = outpatient; DP = day patient; IDU = intravenous drug use*

### 3.4.6 Pain management

Six studies<sup>6 15 73 76 84 93</sup> reported on adequacy of pain management using the pain management index (PMI) as described by Cleeland et al<sup>96</sup> (Table 3-7). The PMI provides a score from -3 to +3 with scores  $\geq 0$  interpreted as adequate pain management. In all these studies, the majority of the participants were receiving inadequate pain management (PMI < 0) with results ranging from 100% of rural and urban South Africans with severe pain scoring PMI < 0<sup>15</sup> to 66% of HIV+ inpatients at a South African hospital scoring < 0<sup>93</sup>.

Table 3-7: Summary of reported pain management index (PMI) scores

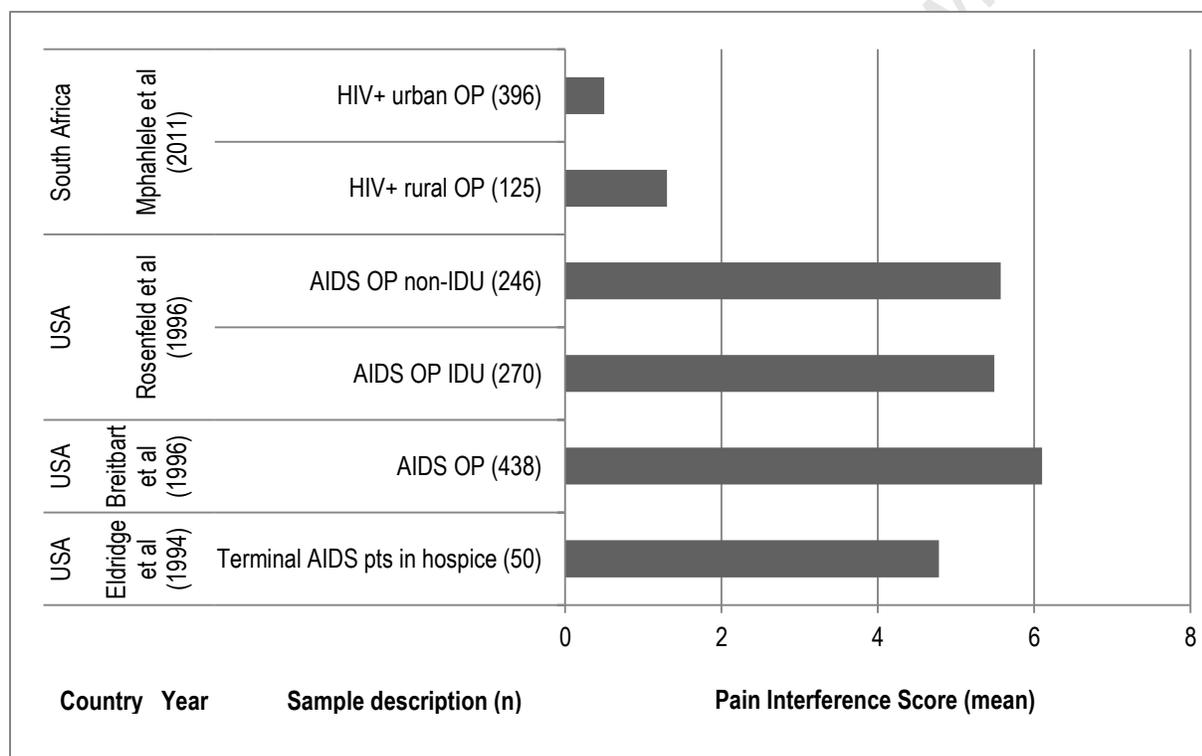
Author (year) <sup>ref</sup>	Setting	Population (sample size)	Pain prevalence (%) (period)	PMI (% < 0)
Larue et al (1997) <sup>6</sup>	13 cities across France	HIV+ IP and OP (290)	62; 53; 30 (IP; DP; OP) (1 week)	85
Breitbart et al (1997) <sup>73</sup>	New York, USA	Ambulatory AIDS patients (516)	63.6 (2 weeks) [67 (IDU); 59 (non-IDU)]	90.4 (IDU) 83.5 (non-IDU)
Frich & Borgbjerg (2000) <sup>76</sup>	Copenhagen, Denmark	AIDS patients at a Dept. of Infectious Diseases (95)	74 (point prevalence)	77
Aires & Bammann (2005) <sup>84</sup>	Sao Paulo, Brazil	HIV+ IP on admission (197)	54.3 (2 weeks)	83
Mphahlele et al (2011) <sup>15</sup>	Urban and rural South Africa	HIV+ OP (Rural 125; Urban 396)	72 (rural) 66 (urban) (point prevalence)	100 (rural – severe pain) 100 (urban – severe pain) 100 (rural – moderate pain) 92 (urban – moderate pain)
Narasimooloo et al (2011) <sup>93</sup>	Kwazulu-Natal South Africa	HIV+ IP Urban district hospital (100)	91 (point prevalence)	66

IP = inpatient; OP = outpatient; DP = day patient; IDU = intravenous drug use

Three other studies reported on the adequacy of pain management<sup>71 88 95</sup>. All three studies reported on the percentage of participants receiving no treatment for their pain. In a Canadian sample, 40% were receiving no analgesia for their pain<sup>71</sup>, 60% of the sample from Nigeria were receiving no treatment<sup>95</sup> and 73% of the participants in the study from India were receiving no treatment for pain<sup>88</sup>.

### 3.4.7 Pain interference with function

Nine studies reported on pain interference with function<sup>14 15 71-73 78 88 93 95</sup>. In four of the studies, the pain interference score from the BPI [no interference (0) – completely interferes (10)] was reported to range from 0.5 (95%CI 0 – 1.3) in a group of urban South Africans<sup>15</sup> to 6.1 in a sample from the USA<sup>14</sup> (Figure 3-10).



OP = outpatient; IDU = intra-venous drug users

Figure 3-10: Summary of mean pain interference scores (n = 1525)

Pain interference with specific functions was described in six studies<sup>14 71 72 88 93 95</sup>. The frequency of pain interference with different aspects of function is summarised in Figure 3-11. All six studies reported on pain interference with sleep; while pain interference with mood<sup>14 72 88 93 95</sup> and with work were reported in five studies each.

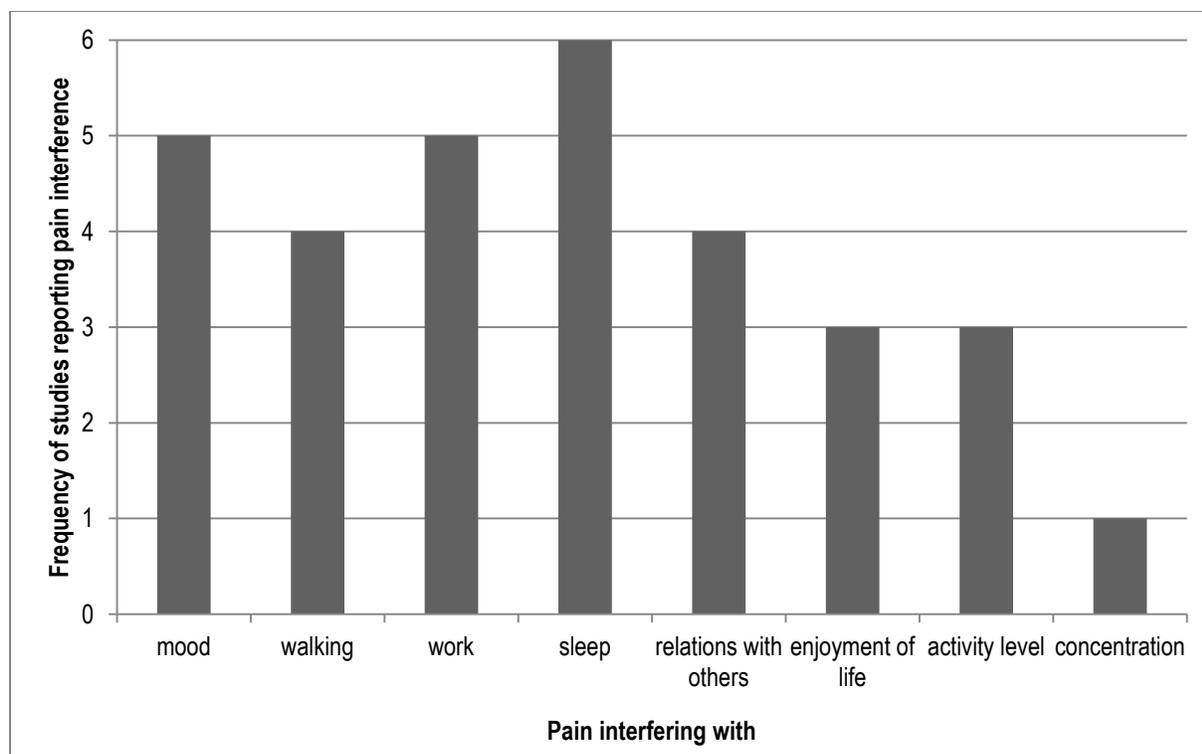


Figure 3-11: Frequency of studies reporting pain interference with different aspects of function

### 3.4.8 Summary of results

Twenty-eight studies were selected for review based on methodological quality. The majority of the studies were conducted in high income countries using samples of convenience dominated by males. The most commonly used instrument to measure pain was the Brief Pain Inventory (BPI). A range of prevalence rates were reported, with an increase in prevalence rates observed as the length of time of the recall period increased from point prevalence (54.9%, 95%CI 51.14 – 56.09), to one-week (55%, 95%CI 57.71 – 62.84), two-week (62%, 95%CI 54.59 – 61.25), and one month (67%, 95%CI 65.9 – 69.24) prevalence rates.

Factors identified as contributing to pain included stage of disease, pharmacological management of HIV/AIDS, IDU, demographic factors and psychological factors. Six studies reported on the number of anatomical sites with pain, five of these reporting multiple sites of pain with the lower limbs and the head being the most commonly reported anatomical sites of pain. Nine of the studies reported on pain management with all of these studies concurring as to the marked under-treatment of pain in the samples. Moderate levels of pain interference with function were reported in nine studies.

Based on this information, and allowing for the lower representation of females in the samples, the typical person living with HIV/AIDS and suffering pain would be female with a possible history of IDU. She would have AIDS, not be receiving ART and be experiencing psychological distress or suffering from a mental health disorder. She would have more than one site of pain, one of which would be the lower limbs or the head, with moderate to severe pain severity and moderate pain interference with function. Finally she would have marked under-treatment of her pain. The relevance of this data with particular reference to the clinical management of PLWHA and future research into pain and its management in PLWHA and will now be discussed.

## **3.5 Discussion**

The aim of this systematic review was to explore the prevalence of pain in PLWHA, the characteristics and contributing factors to pain, pain management and the impact of pain in PLWHA. The results of the 28 studies selected for review will be discussed in the order presented in Section 3.4 Results (p. 20).

### *3.5.1 Methodological Strength of the Studies*

Evaluation of the methodological strength of the studies was based on the 11-item appraisal tool developed for this review. The three specific components relating to study strength were: representativeness of the sample; methodological quality and definition of pain as a symptom. The studies accepted for this review, based on methodological quality, scored a minimum of 73% on the appraisal tool (the mean score of the 66 studies appraised was 67%). It is recommended that good quality prevalence studies should score a minimum of 70% on methodological appraisal<sup>67 69 70</sup>. It would appear that the studies accepted for this review were of high quality. However, the appraisal tool was developed specifically for this study and has not been validated; consequently the appraisal scores should be evaluated with some caution. The studies with higher methodological scores reported slightly higher prevalence rates than those not selected. However, this difference was minor. Weaknesses were identified in relation to the three criteria evaluated.

#### 3.5.1.1 Representativeness of the sample

With regard to the three criteria relating to the representativeness of the sample, 24 of the 28 studies reviewed used a sample which consisted of an entire target population or a randomly selected sample. This could suggest that the study data may be generalizable however, only two of the studies used samples randomly selected to represent an entire nation's population of PLWHA<sup>82 94</sup>. The remaining 22 studies' samples were representative of PLWHA attending specific health care facilities or patient support structures.

The four studies which did not meet this criterion, used samples of convenience (which may have introduced a selection bias), and failed to report any sample size calculation making evaluation of representativeness of the samples impossible<sup>14 73 74 95</sup>.

The categories relating to response rates and non-responders were less well reported. Nineteen of the studies reported reasons for non-responders but only 16 of the studies reported response rates (one study used an entire target population and as such these two categories were marked as not applicable). A lack of information regarding response rates and on the characteristics of non-responders vs. responders limits generalizability of the data as sources of bias cannot be excluded.

The studies were dominated by male subjects from high income countries living in urban areas. Once again this limits the generalizability of the data to females, or to those living in lower income countries or in rural areas. Several studies have recognised the effects of culture and gender on pain experience with differences in pain coping strategies being reported in different ethnic, social and gender groups<sup>97 98</sup>, factors which are not adequately represented in these studies as a consequence of the bias towards samples from high income countries where HIV/AIDS has a greater impact in males. It is ironic that the majority of studies were conducted in populations with relatively low prevalence rates of HIV/AIDS. This may be a reflection of resources in countries with higher prevalence rates needing to be used for the treatment of this population, limiting research.

#### 3.5.1.2 Methodological quality

There were five criteria used to evaluate methodological quality of the studies. All 28 of the studies reviewed included adequate description of the sample including age, sex, stage of HIV/AIDS and or information on CD4+ count. While there were some differences between studies in methodology including sampling methods, on statistical analysis, there were no significant differences in prevalence rates between studies of different designs.

The final criterion evaluated with regard to methodological quality was whether the data had been collected directly from the participants. Only one study did not fulfil this criterion with the data being collected retrospectively from patient folders introducing the risk of a reporting bias<sup>72</sup>. On analysis there was no significant difference in the prevalence rate reported in this study compared with studies where data was collected directly from participants. On the whole, the methodological quality of the studies reviewed was high increasing the validity of the results.

### 3.5.1.3 Definition of pain as a symptom

Several systematic reviews reporting on the prevalence of painful conditions emphasise the need to have a clear definition of pain as a symptom and, the need for further information relating to pain such as severity and pain interference<sup>67-70</sup>. In any prevalence study, prevalence recall periods must be clearly stated. This additional information on pain provided in 26 of the studies reviewed, increases the clinical relevance of the findings.

Only one of the studies reviewed included 95% confidence intervals when reporting the prevalence of pain. The lack of information relating to confidence intervals in the remainder of the studies weakens the interpretation and generalizability of the data<sup>99</sup>. The methodological quality of the studies as determined with the appraisal tool designed for the review appeared good with the main areas of weakness relating to the representativeness of the samples limiting the generalizability of the data.

### 3.5.2 *Description of the studies*

An exploration of the number of studies published per year included in the review may be a reflection of a growing awareness of pain as a problem for PLWHA (Figure 3-2, p.26). There were six studies published in 2011 in the review, compared with only one study per year in 1993 and 1994. However, exploration of the number studies published per year using all 66 of the papers reviewed, (Appendix A:, Figure A-1, p. 247), suggests that although there has been an increase in the overall number of studies published on pain in PLWHA, the numbers presented in this review reflect an increase in studies of higher methodological quality in recent years. This is perhaps not unexpected as the publication of guidelines for the reporting of observational studies (STROBE guidelines<sup>66</sup>) and similar papers have provided researchers with clear direction to assist in improving the quality of research.

### 3.5.3 *Prevalence of pain*

There was a range in prevalence rates reported across the studies. The biggest variation was in point prevalence rates from 10.9% in the Vietnamese population survey<sup>94</sup> to 91% of HIV+ inpatients at an urban hospital in KwaZulu-Natal, South Africa<sup>93</sup>. Despite these ranges, on analysis there was no difference in the median and mean point prevalence, one-week, two-week, one month and three month prevalence rates for pain. The large ranges of prevalence rates may reflect a variation in sample characteristics such as differences in gender representation and cultural differences as well as differences in stage of disease, availability of ART and differences in type of HIV infection.

The relatively small increase in point, one-week; two-week, one-month and three month prevalence rates is notable as it could suggest that the factors contributing to pain are chronic despite variations in treatments; acute exacerbations of illness, and daily or weekly variations in psychosocial factors. Notably the two week prevalence rates were all recorded using the same instrument (BPI). These studies were conducted in diverse settings (low-and high-income countries) with samples of PLWHA ranging from asymptomatic HIV+ outpatients to inpatients with AIDS. The use of the same instrument facilitates pooling of the data and the mean two-week prevalence rate of pain of 62% may be a fair reflection of the two week prevalence rate for PLWHA in diverse settings at all stages of the disease.

The consistent prevalence rates from the earliest reviewed study published in 1993<sup>71</sup> to the studies published in 2011, are also notable. Across all the prevalence periods (point prevalence through to one month prevalence), prevalence rates have not decreased in recent studies.

Despite an increasing awareness of pain as a problem for PLWHA, the problem of under-management persists. This raises two questions relating to the clinical management of PLWHA. The first is the question of whether the data on pain as a problem for PLWHA is being effectively distributed to clinicians working with this patient group. Alternatively, if the information is reaching the clinicians, under-treatment could result from a lack of effective pain management treatment strategies for this patient group. Factors which contributed to the presence of pain in different samples were explored in several of the studies. These contributing factors will now be discussed further.

#### 3.5.3.1 Stage of disease and presence of pain

The relationship between stage of disease and the presence of pain was explored in eight of the studies reviewed<sup>14 75 79 82 88-90 95</sup>. Overall it would appear that a more severe disease profile as recorded by stage/category or CD4+ count is associated with a higher prevalence of pain, but, the disease severity only seems to partially account for pain prevalence. The fact that three studies reported no association between pain prevalence and disease stage<sup>14 79 95</sup> suggests that a number of other factors may interactively contribute to pain.

#### 3.5.3.2 Pharmacological management and presence of pain

Two studies specifically reported on the relationship between pharmacological treatment and the prevalence of pain<sup>14 89</sup>. These results were conflicting with one study showing a decrease in pain with ART<sup>14</sup> and the second, more recent study reporting no difference in prevalence rates between those receiving and not receiving ART<sup>89</sup>. As with the data on pain and disease severity, this conflicting data suggests that the disease mechanisms influenced by ART may play a role, these are not the only factors contributing to the presence of pain in PLWHA.

### 3.5.3.3 Intravenous drug use and presence of pain

An increased prevalence of pain in those with a history of IDU may be a reflection of under-management of pain in this sub-group as a consequence of patient and clinician fears of addiction<sup>100 101</sup>. However, the data from Martin et al<sup>75</sup> showing that pain in the IDU group does not follow the same pattern as the non-IDU group suggests that there are variables other than treatment which influence the presence of pain. Consideration of pain as a biopsychosocial construct requires exploration of the psychosocial in addition to the biological factors as contributors to pain.

### 3.5.3.4 Demographic factors and presence of pain

Women were clearly identified as having higher pain prevalence rates in several studies<sup>14 82 90</sup>. There is a plethora of literature discussing the complexity of pain and differences in pain perception and responses between the sexes<sup>102-104</sup>. It is recognised that men and women respond differently to nociceptive input due to physiological differences in functioning<sup>102-104</sup>. However, differences in response may equally be affected by cultural gender differences, that is differences in culturally accepted or expected behaviour by men or women<sup>103 105 106</sup>. Hence, the results from Hitchcock and colleagues<sup>86</sup>, the only study reporting a higher prevalence of pain in men, needs to be considered in the context of the specific ethnic group which was represented in their sample. Exploration of the setting of their study (Tshwane, South Africa) may provide insight into the ethnic groups and cultures which may have been represented. Unfortunately, a lack of description of ethnic group and cultural variables in the sample limits further understanding of what factors may have contributed to this result.

With regard to ethnic groups, three studies with diverse ethnic groups reported a higher prevalence of pain in black participants<sup>82 90</sup> and a further study reported a higher prevalence of pain in non-Caucasian groups<sup>14</sup>. Studies exploring differences between African-American and white American groups have identified differences in pain prevalence between these groups in both healthy adults and chronic pain populations with African-American populations having a higher prevalence of chronic pain<sup>97 107</sup>. Differences in ethnic groups have been also been reported in response to experimentally induced pain with African-American populations having lower tolerances for heat pain, cold pressor pain and ischaemic pain<sup>108</sup>. Differences in pain prevalence and coping are theorised to be as much a reflection of differences in physiological functioning (ethnicity) as of the psychosocial influence of culture<sup>109 110</sup>. These findings highlight the need for both ethnic and cultural groups to be clearly identified in pain prevalence studies. Description of participants as for example, “white” or “black”, allows limited interpretation of data with inferences on different prevalence rates being restricted to biological mechanisms. Categorisation according to both ethnic and cultural groups provides greater insight into the role of both genetics and culture in pain and aligns research within the biopsychosocial model of pain.

### 3.5.3.5 Psychological factors and presence of pain

All five of the studies reporting on psychological factors as contributors to pain found psychological distress or psychological illness associated with an increase in pain<sup>74 77 81 89 92</sup>. These results concur with previous studies which have identified the strong influences of psychosocial factors on pain in a wide range of painful pathologies<sup>111-114</sup>. Psychosocial factors such as attitudes towards pain, behaviours and emotional issues have been found to increase the risk of developing chronic low back pain<sup>115</sup>, while depression, anxiety and post-traumatic stress disorder have also been recognised to contribute to the incidence and severity of pain<sup>116 117</sup>. It is proposed that these factors sensitise the central nervous system pain neuromatrix (as presented in Chapter 1) increasing the pain experience. In addition, pain is recognised as a symptom of mood disorders such as depression<sup>118</sup>. Therefore pain in the presence of both HIV/AIDS and depression may be a symptom of either and be worsened by the presence of the additional condition. Further, the stresses of being diagnosed with HIV/AIDS coupled with other psychosocial factors such as the stigma associated with being HIV-positive may combine and lead to increased susceptibility of pain.

Information on the characteristics of the pain experienced by PLWHA including the severity and sites of pain reported in the studies reviewed will now be discussed.

### 3.5.4 *Characteristics of pain*

The studies reviewed reported that PLWHA commonly present with multiple sites of pain with a range of pain severity. Multiple pain sites suggest that there are several differing pathological processes contributing to pain at one time. This reinforces studies reporting various causes of pain in PLWHA, from the virus itself to opportunistic infections to side effects of treatment<sup>46</sup>. While there is a growing body of research focusing on painful peripheral neuropathies in PLWHA<sup>119</sup>, sites of pain in the studies reviewed, were not restricted to the peripheries indicating that other mechanisms need to be explored.

The presence of severe pain in large portions of the samples in several studies is notable as increasing pain severity is associated with an increase in functional interference<sup>86</sup>. It is recognised that pain interrupts activities, inhibits cognitive processing and ultimately changes identity<sup>114</sup>. While chronic pain management programmes advocate that function does not need to be limited by pain, and that quality of life can be restored despite pain, this is difficult to achieve in the presence of severe pain. The focus of treatment in chronic illnesses (once risk of mortality has been reduced) is to maximise quality of life; however, severe pain interrupts activities and ultimately interferes with function further reducing quality of life, not simply through suffering but also through the consequent inhibition of participation in meaningful activity.

In summary, the high prevalence of pain coupled with multiple pain sites and severe pain reported in these studies indicates that pain is a significant symptom for PLWHA which needs adequate management to reduce suffering and restore quality of life. Exploration of pain management in the studies reviewed will provide an indication of the effectiveness of pain management.

### *3.5.5 Pain management*

All the studies reviewed which reported on pain management indicated a concern about treatment of pain in the samples. These results are especially alarming in studies where over 90% of participants with pain were not receiving adequate pain management and many were receiving no treatment for pain at all. There are several barriers which may contribute to the under-management of pain in PLWHA<sup>101</sup>.

These barriers may relate to the patient such as patients not realising that the pain is related to their disease, fear of what the pain may mean, fear that the clinician may be distracted by the pain, fear of being labelled as a difficult patient and a lack of understanding that treatments other than HAART are available<sup>100</sup>. However, all responsibility does not lie with the patient; several clinician related barriers have been identified such as a lack of awareness about pain as a problem<sup>76</sup>, a lack of access to adequate analgesia<sup>120</sup>, fear of addictions<sup>76 121</sup> and finally a lack of time in consultations<sup>121</sup>. Despite these barriers being identified, some of them as long as 10 years ago, data in the more recent studies reviewed indicate that pain management in PLWHA has not improved.

One component which was not explored in relation to pain management for PLWHA in the studies reviewed was the non-pharmacological management of pain. Pain management interventions using exercise<sup>122-125</sup>, relaxation or mindfulness based techniques; cognitive behavioural therapy and patient education have been recommended for PLWHA<sup>2 126-128</sup>. However, the use and effectiveness of these techniques in managing pain was not reported on in any of the studies reviewed.

### *3.5.6 Pain interference with function*

Nine of the studies reviewed reported on pain interference with function in addition to pain prevalence and severity. Measuring pain interference with function is a recommendation of the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT)<sup>129</sup>. These recommendations recognise that it is not merely the presence of pain which contributes to patient suffering and decreased quality of life but that pain interference with function further compounds the effect of pain.

Four of the studies reported a pain interference score on a scale of 0 – 10 (no interference – maximum interference). The median score for pain interference from these studies indicated moderate pain interference with function. The broad range of activities which were reported to be affected by pain and the moderate level of interference reiterate the impact of pain on quality of life in PLWHA.

The most commonly reported activity affected by pain was sleep (reported in six studies) with mood and work being reported in five of the studies reviewed. Patients reporting pain interference with sleep is of particular concern when the links between sleep and pain, specifically headaches<sup>130</sup> and widespread musculoskeletal pain<sup>131</sup> are explored. Pain interference with function has the potential to further sensitise the CNS and increase the number of pain sites and pain severity resulting in a worsening spiral of symptoms<sup>132</sup>.

### *3.5.7 Strengths of the review*

The strengths of this review include the clearly defined inclusion criteria and search strategy. The search strategy was repeated at a later date and no additional articles were identified. The use of a flow diagram describing the search and screening process further clarifies the procedure followed. The use of two independent researchers to screen abstracts strengthens the systematic review limiting bias and minimising exclusion of possibly relevant publications.

Summary tables and graphs of the studies' findings allow for clear viewing of the data and facilitate interpretation and pooling of results. The use of the BPI by several of the studies further strengthened the review as it allowed for pooling of the data.

### *3.5.8 Limitations of the review*

Limitations of this review relate to the methods used to conduct the review and the quality of the data reviewed. The search terms used included "pain" which may have introduced a selection bias into the search. Firstly, studies conducted on the impact of HIV/AIDS on functioning and participation which could have explored pain as an impairment may not have been identified using this search criteria. Secondly by using the term "pain" in the search, the search was biased towards finding studies reporting on the problem of pain. Studies which explored pain but did not identify it as a problem may not have used the term as a key word. The use of the term "impairment" in the search rather than "pain" may have limited this bias.

The search was restricted to articles published in English due to the language limitations of the researchers. This may have resulted in the exclusion of relevant literature from the review at the outset. Further, only one reviewer screened the full text articles and administered the 11-item methodological screening tool. Ideally, this procedure should be conducted by two independent researchers to ensure consensus in scoring and subsequent selection of studies. In the interests of reproducibility, only published studies were included in this review and manual searching of journals not indexed in electronic databases was not performed. This could introduce a publication bias as unpublished studies and studies published in lower circulation journals may report results against the trend of those previously published.

### **3.6 Conclusion**

The aims of this systematic review were to establish the prevalence of pain, characteristics and contributing factors to pain, whether pain is adequately treated and the functional impact of pain in PLWHA. The results of this review highlight that pain is present in between 55% - 67% of PLWHA at all stages of the disease with prevalence rates increasing with the length of the recall period. The prevalence rates for pain in PLWHA do not appear to have diminished over the 30 years spanning the studies reviewed despite large scale roll-out of ART world-wide.

In terms of pain characteristics, the pain reported by PLWHA is of moderate to severe intensity. Moderate to severe pain is recognised to have significant impact on ability to function and quality of life. When present, pain in PLWHA occurs at more than one anatomical site. The most commonly reported sites of pain were the lower limbs followed by head pain suggesting that there are variable causes of pain in PLWHA. Bilateral lower limb pain is characteristic of painful peripheral neuropathy but the varied anatomical sites of other pain including head pain are less characteristic of specific conditions.

Several factors were identified as contributing to pain. A history of IDU, being female and of African-American descent increased risk of pain. Several studies reported that depression, anxiety and a lack of social support increased risk of pain as did lower levels of education. The interplay of these variables suggests that the biopsychosocial model of pain is an appropriate paradigm from which to view pain in PLWHA. Although the biopsychosocial model has been criticised for its lack of structure which would facilitate analysis of the weighted contribution of variables<sup>133</sup>, in a complex construct such as pain in HIV/AIDS, it is still a useful frame from which to approach the problem, explore causes and establish effective treatment.

The pain affecting PLWHA also has functional effects as reported by pain interference measures and these functional effects have consequences for health related quality of life. Several studies used the pain interference score from the BPI to measure global pain interference. Sleep was the most commonly identified item, followed by interference with ability to work and interference with mood emphasising the global impact of pain on both the PLWHA and society. This emphasises the need to address pain not simply to prevent suffering but to facilitate function.

### *3.6.1 Clinical implications*

In all the studies reviewed the majority of PLWHA who were experiencing pain were receiving inadequate treatment for their pain. It is concerning that despite the institution of an international Task Force on Pain and AIDs in 1994<sup>44</sup>, there is still marked under-treatment of pain in PLWHA. The dissemination of this systematic presentation of cumulative data in this review might be useful to motivate clinicians to address this symptom and its effects in PLWHA by emphasising the severity and scale of the problem of pain in PLWHA.

The body of work available in the literature thus far, while emphasising the problem of pain for PLWHA has not had an impact on the management of this symptom. The lack of association between pain and pharmacological treatment of HIV (ART) indicates that treatment or management of the virus is not sufficient to manage pain. Further, the varied factors which have been found to contribute to pain imply that the biopsychosocial model is a useful paradigm for clinicians to use in addressing not only nociceptive (biological) contributors to pain but also psychosocial factors such as depression and anxiety. Thus specific assessment of pain at each clinical visit is recommended with clear guidelines for the pharmacological and non-pharmacological management of any pain present.

### *3.6.2 Research implications*

This review has highlighted several factors which researchers should consider in planning further research into pain in PLWHA. The under representation of populations from low-income countries and females in the studies reviewed, indicates the need for further work in these groups. The identification of ethnicity as a contributing factor to pain suggests that ethnicity and cultural factors should be carefully considered. Broadening the focus of studies to explore pain in PLWHA using a biopsychosocial approach may help identify factors which can be modified through both pharmacological and non-pharmacological treatments. Finally, the under-treatment of pain in PLWHA continues to be a concern and a research focus on optimizing pain management is indicated. In the next chapter, measurement instruments selected for use in a study on pain in a specific sample of PLWHA will be presented.

# Chapter 4: Instrumentation – selection and translation

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## 4.1 Introduction

Effective research relies on valid and reliable measurement instruments<sup>24</sup>. The use of standardised measurement instruments which have cross-cultural validity is essential in research and creates the potential for meta-analyses of studies<sup>134 135</sup>. As was evident in Chapter 3, instruments which are reliable, valid and with clinical utility are needed to record pain prevalence and facilitate comparison of results. There are debates in the literature regarding the development of valid instruments for use in cross-cultural research which bear consideration when selecting instruments.

One argument is that research instruments which are to be used in different cultures should be developed from the perspective of the cultures under investigation<sup>136 137</sup>. Herdman and colleagues<sup>136</sup> refer to this as a universalist approach in which researchers do not assume that constructs remain the same across cultures. This approach may be challenging, costly and beyond the scope of most researchers as preliminary qualitative studies of each culture may be required with the subsequent development of an instrument by a multicultural team deciding on concepts/items which are of equal importance for each cultural group<sup>136 137</sup>. In addition to being costly and lengthy, the approach limits comparison of study results to previous research or to research in different cultural groups which have used different instruments.

In contrast, an absolutist approach assumes that constructs will remain constant across cultures. This approach is often favoured due to its relatively simple approach of translating instruments from one language to another allowing for the generation of data which is comparable across cultures<sup>138</sup>. However, absolutist translation or the assumption that translation will produce an instrument acceptable in another culture with no exploration of the role of culture has questionable validity. Hence, the contrasting universalist and absolutist approaches need to be carefully considered in cross-cultural research.

The opposing approaches of absolutist vs. universalist overlap with the emic and etic positions presented by some authors in cross-cultural research<sup>134</sup>. The emic refers to the notion that a word or phrase will have a particular meaning for a particular cultural group which might not be transferrable to another cultural group. The etic refers to the notion that a word or phrase maintains its meaning between cultures.

The process of obtaining measures of phenomena is essentially an etic or absolutist activity – it requires the researcher to assume that all those responding to the instrument will interpret it equally. However, in order to translate this activity, an emic or universalist approach needs to be adopted to ensure that the measure achieves its objective in the target culture<sup>139</sup>.

An integrated theoretical framework has been proposed for use in cross-cultural psychiatry<sup>140</sup>. This integrated approach allows researchers and clinicians to adopt a “middle road” where the contribution of absolute biological factors and universal social factors can be realised. The adoption of a similar integrated approach in the adaptation of a measurement instrument would acknowledge that while some components are constant across cultures (such as the biological contributors to pain such as nociception), other components will vary depending on language, culture and context (such as different responses to pain across gender or age groups or different interpretations of what pain means). It is proposed that an integrated approach be adopted in the development of measurement instruments which will have cross-cultural validity, reliability and clinical utility.

The objective of translation is therefore, to achieve a culturally equivalent instrument which has the same connotative meaning as the original<sup>141</sup>. It should be recognised that a measurement instrument will be specific not only for the language group but also for the cultural group. Once the role of culture is recognised it is logical that the etic-absolutist approach is limited and that integrating it with the emic- universalist view in which researchers do not assume that constructs will be the same across cultures will strengthen the validity, reliability and clinical utility of the final instrument<sup>136</sup>. Therefore, the translation of a measurement instrument using an integrated approach refers to the dual processes of language translation and cultural adaptation.

#### *4.1.1 Theoretical approach to translation*

In the cross-cultural adaptation and translation of measurement instruments, the theoretical approach of the translators will strongly influence the equivalence of the translated instrument<sup>136</sup>. As mentioned previously, a researcher adopting the absolutist approach assumes that there will be little change in the content and concepts of an instrument if careful attention is paid to linguistic translation; in contrast to an universalist approach in which the researcher does not assume that constructs will be the same across cultures exploring the relevance of the content and concepts of the instrument to the target culture prior to translation<sup>136</sup>.

The majority of published and widely used measurement instruments were developed and tested in countries whose cultural worldview is strongly Anglo-American<sup>135</sup>. In order to balance the effect of the originating culture on the instrument, the translation process must be carefully structured and a decentred approach adopted in which equal value is given to both the originating and the target languages and cultures<sup>142</sup>. A poorly conducted translation may result in a loss of validity because of a change in meaning. There may be a loss of semantic meaning (i.e. incorrect choice of language or word selection), or, because of inadequate cross-cultural adaptation of the instrument, a loss of connotative meaning (i.e. culturally the instrument may explore issues which are not culturally acceptable or which hold no cultural meaning)<sup>135 142</sup>.

An effective translation procedure will result in a measurement instrument which is both a linguistic and cultural equivalent of the original. The procedure needs to be rigorous and able to withstand the challenges which are certain to arise as a consequence of cultural and linguistic differences. Several methodological approaches have been described with the aim of achieving valid, culturally appropriate translations<sup>134 135 137 138 141-143</sup>. While some differences exist in these methodologies, the adoption of an integrated approach balancing the etic-absolutist with the emic-universalist approach facilitates cultural equivalence<sup>134-136 139 143</sup>. These methodological approaches will now be discussed.

#### 4.1.2 *Translation methodologies*

The recognition of the need for standardised instrumentation has led to the development of standardised methodologies for translation<sup>134</sup>. Recognising the contrasts between the emic and etic approaches and the need to integrate these approaches, Flaherty and colleagues<sup>134</sup> described two stages in the process of developing psychiatric instruments for cross-cultural research. As a first step, a careful review of the literature is done to identify a measurement instrument which is psychometrically sound. Once an appropriate instrument has been selected the authors propose a stepwise validation process to ensure equivalence in five dimensions; namely:

1. Content equivalence – the content of the instrument should be culturally relevant
2. Semantic equivalence – relates to whether each item has the same meaning in the language or idiom of each culture
3. Technical equivalence – relates to whether the method of assessment or method of data collection used with the instrument is equivalent in each culture
4. Criterion equivalence – interpretation of the instrument is constant in both cultures when compared with the norm for each culture
5. Conceptual equivalence – evaluation of whether the instrument is assessing the same theoretical construct and domains as in the originating culture.

The authors propose that an instrument which meets all five dimensions of equivalence is a culture-free instrument as opposed to one which is culture-bound. In reality, a completely culture-free instrument is probably impossible but the aim of cross-cultural translation is to achieve maximum equivalence in all five dimensions.

The approach proposed by Flaherty et al<sup>134</sup> is reinforced by Herdman and colleagues<sup>136</sup> in a more recent paper. Herdman et al stress the importance of adopting a universalist approach when translating health related quality of life measures. However, the authors presume that quality of life is a concept which exists in other cultures, essentially initiating the process from an absolutist standpoint. Hence it could be suggested that the authors are proposing an integrated approach recognising the role of both absolute and universal views. Herdman et al recommend initially using qualitative methodology in order to elicit aspects of concepts which are truly universal across cultures<sup>136</sup>. While the authors identified six types of equivalence very similar to those proposed in the earlier paper by Flaherty et al<sup>134</sup>; the types of equivalence are prioritised differently with an initial emphasis on ensuring conceptual equivalence through qualitative study to ensure a universal instrument in which each culture is given equal value. The six domains identified in this model are:

1. Conceptual equivalence – this is defined in the same way as Flaherty et al<sup>134</sup>. However, the authors emphasise that *post hoc* analysis of the translated instrument (as recommended by Flaherty et al<sup>134</sup>) as the final step of the process, is not sufficient to achieve equivalence. Rather, they recommend a qualitative methodology as the first step in order to ensure that all domains are equally relevant in both cultures to ensure a universalist approach.
2. Item equivalence – relates to the relevance of individual items to each culture and corresponds to “Content equivalence” listed above.
3. Semantic equivalence – this is defined in the same way as Flaherty et al<sup>134</sup>. The authors further expand on this concept by identifying the need to ensure that different types of meaning are translated including referential, connotative, stylistic or social, affective, reflected, collocative and thematic meaning.
4. Operational equivalence – this is effectively the same as the “Technical” category described by Flaherty and colleagues with the authors recommending similar procedures.
5. Measurement equivalence – this is similar to the “Criterion equivalence” above.
6. Functional equivalence – the extent to which the instrument measures the construct it is intended to measure in the cultural group it is being applied in. This final type of equivalence is aimed at drawing all the previous together in order to evaluate the global equivalence of the instrument. In order to assess this type of equivalence each of the previous categories must be evaluated <sup>136</sup>.

In the present study the aim was to identify appropriate instruments for the measurement of pain and factors which may contribute to pain in an urban population of amaXhosa women. In order to adequately measure and understand the constructs being explored, an integrated approach to translation is adopted in which both biological (etic-absolutist) and social (emic-universalist) contributors are given value.

Methods described to achieve semantic equivalence of instruments include one-way translation and varying methods of back-translation including a committee approach<sup>134 135 138 139</sup>. These methods will now be discussed further.

#### 4.1.2.1 One-way translation

One-way translation is possibly the least valid method to use when aiming for an instrument which has cross-cultural acceptance. The method is dependent upon a single bilingual translator and is totally reliant on that individual's skill in language and culture<sup>137</sup>. This method, although often used because of its simplicity and limited costs, frequently results in translated instruments with low validity and reliability.

#### 4.1.2.2 Back translation

Back translation uses a team of translators which independently perform the forward translation and back translation of the instrument. Although a minimum of two translators is sufficient, many authors recommend at least four translators, two translators to perform forward translation and another two translators to perform back translation – essentially a committee approach<sup>137 138 141</sup>. The method using only two translators is not as robust with a risk of errors such as obtaining literal but not semantic equivalence<sup>144</sup>.

Several authors recommend the committee approach using a minimum of four translators<sup>136-138 141 144-146</sup>. In order to avoid the original language and culture dominating the translation process, both cultures need representation in the translation team<sup>144</sup>. Both forward translators' first language should be the language the instrument is being translated into, with one of the translators having medical knowledge appropriate to the instrument to facilitate clinical equivalence and the second translator being naïve in this aspect to ensure cultural equivalence<sup>138</sup>. This can be seen to be integrating the etic-absolutist and emic-universalist approaches. Further, some authors recommend that the back translators' first language should be that of the original instrument<sup>137 138 141</sup>. However, this can result in the target language and culture being underrepresented and errors may ensue due to inherent correction of translated material into grammatically correct versions of the original language rather than direct translation of material<sup>144</sup>. If the translators are not carefully selected and briefed it is possible that adequate decentring is not obtained with the original language and culture still dominating the process.

In order to achieve cultural equivalence, adequate decentring with the translation team able to paraphrase ideas and concepts into the target language and appropriate to the culture is essential<sup>141 147</sup>.

In addition to recommendations on language, and medical expertise, other factors which influence language and communication in different cultural groups should be accounted for in the selection of translators. For example, different age groups may use different language and interpret questions differently in some cultures, thus representatives of all age or social groups may be an advantage in a translation team<sup>148</sup>.

Using two translators to perform the forward translation means that a synthesised version of the translations be agreed to, facilitated by an independent researcher<sup>138</sup>. This production of a synthesised version also allows for decentring with the input from the translator with medical knowledge and the naïve translator integrated. The synthesised translation is the version provided to the back translators. In addition, the back translators should be blinded to the original instrument in order to prevent bias in the translation<sup>141</sup>.

Finally in order to ensure semantic, idiomatic, experiential and conceptual equivalence, further validation procedures need to be followed. Sperber<sup>144</sup> suggests comparing results obtained with the source language original scale with results obtained with the source language back translation scale as a means of validation. While this may appear to be a robust approach, it only provides information on the interpretation of the instrument by the cultural group in which it originated. It is not a decentred method giving each language and culture equal value but rather reflects an absolutist approach. An integrated committee approach in which both languages and cultures are represented equally with additional input from medical experts as reported in several papers appears optimal<sup>138 139 141 149</sup>. In this approach, a committee inclusive of the translators, the researchers and representatives of the cultural groups in which the instrument will be used ensures optimal integration. The use of a committee allows for consolidation of different versions of a questionnaire and consensus can be reached on difficult items. In this process, the committee should have access to all versions of the instrument including notes highlighting any areas of difficulty encountered in the process<sup>138</sup>. The inclusion of researchers with expert knowledge on the objective of the instrument assists the committee in obtaining semantic and conceptual equivalence. The use of a committee therefore, allows for the exploration of the cultural acceptability of a translated instrument with a focus on achieving a meaningful and valid translation of the instrument<sup>144</sup>.

In this chapter, the first step in the process, namely the identification of psychometrically sound measurement instruments will be presented prior to a description of the process followed in the translation of measurement instruments which were not available in isiXhosa. In Chapter 4, the validation and reliability of the translated instruments will be examined.

## 4.2 Selection of instruments

There are a large number of measurement instruments available in the health sciences which have been designed to capture information on a variety of topics. To select instruments which will adequately measure the variables explored, the adoption of a clinimetric approach is useful<sup>150</sup>. This approach encompasses a combination of the biometric approach which focuses on the measurement of biological events and psychometrics which focus on the measurement of psychological events. Considering the theoretical framework of pain as a biopsychosocial construct (Chapter 1: ), a clinimetric approach is appropriate.

In the systematic review presented in Chapter 3, the importance of a valid and widely used instrument for pain and the variables identified to contribute to pain was recognised. These findings are reaffirmed by the recommendations from the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) group that research into pain and pain management should evaluate pain intensity, physical functioning, emotional functioning and patient satisfaction with treatments<sup>151</sup>. The literature was subsequently searched for measurement instruments or scales which would provide information on pain intensity and interference (physical and emotional), and the variables of depression and trauma, childhood trauma, HRQoL and self-efficacy which were identified through the systematic review as having been identified to contribute to pain or to a PLWHA's ability to manage pain. The measurement instruments were evaluated using a clinimetric approach considering issues of content validity, reliability, responsiveness and interpretability<sup>152</sup>. This evaluation was at all times guided by the guiding clinimetric questions of: "What do I want to know?" and "Why do I want to know that?"

### 4.2.1 *Measurement of pain*

The primary variable of interest in this study was pain. There are numerous reliable and valid tools which can be used in the measurement of pain. Several methods and instruments used in measuring pain were reviewed prior to selecting the primary outcome measure. Pain measurement instruments range from single-item instruments which only measure pain intensity using visual analogue scales (VAS), numerical rating scales (NRS) or verbal rating scales (VRS) to longer multiple-item instruments which aim to obtain more information including pain intensity, pain affect, pain interference with function and pain relief<sup>153 154</sup>. Several instruments were considered for use in the present study following a review of the literature and an evaluation of the most commonly used instruments in the studies reviewed in Chapter 3. These included two of the more commonly used multiple-item instruments; the McGill Pain Questionnaire<sup>155</sup> (used in one of the studies reviewed in Chapter 3) and the Brief Pain Inventory<sup>96</sup> (used by several studies reviewed in Chapter 3) and the health related quality of life (HRQoL) instrument the EQ-5D<sup>156</sup>.

As recommended by the IMMPACT guidelines, the instrument selected for the present study needed to measure the presence of pain, sites of pain, pain intensity and the impact of pain on function (pain interference). The unidimensional NRS and VAS for pain are widely used in several indigenous South African languages (including isiXhosa)<sup>157</sup>. While these are rapid and useful tools for assessing pain in a clinical setting, they have limited use in research as they provide no information as to the effect of pain on the patient's function. In addition information on the effectiveness of treatment or on the distribution of symptoms cannot be obtained from these instruments.

The EQ-5D HRQoL instrument includes an evaluation of pain<sup>156</sup> and was used in three of the studies reviewed in Chapter 3. It has been translated and validated in several indigenous South African languages including isiXhosa<sup>149</sup>. The instrument evaluates the presence and severity of pain using a three-tiered ranked scale ranging from "I have no pain or discomfort", to "I have moderate pain or discomfort" and "I have extreme pain or discomfort". Like the NRS or VAS for pain this scale provides an evaluation of pain severity. However, it cannot be assumed that problems recorded on the instrument indicating issues with mobility or activities are due to pain or some other health related cause. Thus its utility for measuring pain interference is limited.

The McGill Pain Questionnaire (MPQ) is favoured by researchers as it provides information on the sensory, affective and evaluative dimensions of pain as well as providing a total pain severity score or pain rating index<sup>155</sup>. The Italian version of the MPQ (IPQ) was used in one of the studies reviewed in Chapter 3<sup>79</sup>. The MPQ consists of 78 words used to describe pain which are grouped into 20 categories allowing for the scoring of pain in the sensory, affective and evaluative dimensions and miscellaneous pain. In addition, the questionnaire includes a body chart where patients can indicate their areas of pain. The MPQ can be used to discriminate between pain which is arising from physical causes and pain in patients with no clear physical cause<sup>158</sup> and some authors have reported that scores on the MPQ are more closely associated with psychological distress than with pain intensity<sup>159</sup>. The MPQ does not measure pain interference with function nor is it as sensitive as other pain instruments to changes in pain<sup>160</sup>, limiting its clinical utility. The use of the instrument thus appears to be limited to assessing pain and not assessing the impact of pain or the impact of treatment on pain. In addition to these limitations, patients with severe pain have reported that the MPQ is too long, has too many responses which are ambiguous and included questions which were not relevant<sup>161</sup>. While the MPQ has been translated and validated into several languages, there is no validated version in any indigenous South African language and its complex semantic structure may present a challenge in translation.

The instrument most widely used to measure pain and its impact in people living with HIV/AIDS is the Brief Pain Inventory (BPI)<sup>14 86 96 100 116 162-165</sup> which was used in 13 of the studies reviewed in Chapter 3. The BPI is a self-administered questionnaire which was initially developed for use by cancer patients but has been validated for use in non-cancer pain and is widely used in other chronic conditions in which pain is a feature<sup>96 163</sup>.

It is available in a short form designed for research and a long form which asks for additional information on the patient's illness history and quality and behaviour of pain<sup>96</sup>. This assessment measure has been found to be sensitive to treatment of pain in AIDS patients and valid when exploring pain related barriers to mobility in AIDS patients<sup>166</sup>.

The simple semantic structure of the BPI has facilitated its translation and validation for use in several diverse populations<sup>146 167-172</sup>. Although the BPI has been previously translated into isiXhosa for use in a study exploring the prevalence of pain in cancer patients in South Africa<sup>173</sup>, the authors did not report on its validation. The Wisconsin Brief Pain Questionnaire (WBPQ), the precursor to the BPI<sup>174</sup> was translated into several South African languages including isiXhosa by Mphahlele and colleagues<sup>12</sup>. The Setswana, IsiZulu and Xitsonga versions of the instrument were validated in rural and urban ambulatory HIV+ patients. Although the instrument was translated into isiXhosa, the small sample of respondents in this group (n = 34) meant that validation of this version was not feasible.

Both the BPI and the WBPQ measure the severity of pain by asking the respondent to rate their "worst" pain, "least" pain, "average" pain and "present" pain on a 0 – 10 numeric scale. The end points on the numeric scale are described as 0 "No Pain" and 10 "Pain as bad as you can imagine". The four pain severity scores ranging from 0 – 10 are averaged to generate a Pain Severity Scale. The BPI asks patients to reflect on pain felt in the previous week, while the WBPQ asks about pain felt in the previous month. While information about pain in the previous month may be useful, the accurate recollection of pain severity over a period of more than a week has been questioned as people tend to over-report the severity of pain over time<sup>153</sup>. This length of time (month) was thus reduced to a week in the newer version of the instrument, the BPI.

Both instruments then ask for information regarding treatments or medications being received for pain and the amount of relief these treatments have provided. Treatment relief is recorded on a 0% - 100% scale with the anchors on the scale being "0% No Relief" and "100% Complete Relief". This section of the instruments allows for the evaluation of the effectiveness of medication on pain through the generation of a Pain Management Index as was reported in Chapter 3 (Section 3.4.6; p. 48).

The final section of both the BPI and the WBPQ consists of seven questions exploring pain interference with activities and quality of life. The seven aspects explored are: "general activity"; "mood"; "walking ability"; "normal work including work outside the house and housework"; "relations with other people"; "sleep" and "enjoyment of life". In the WBPQ these were measured on a 5-point scale ranging from 0 "no interference at all", to 5 "extreme interference". This scaling was changed in the BPI for uniformity to a 10-point scale with end points being termed 0 "does not interfere" and 10 "completely interferes"<sup>175</sup>. These seven scores are averaged to generate a Pain Interference Score as reported on in Chapter 3.

The BPI and the WBPQ contain two elements which are not included in other pain measures which would be of particular use in the present study. The first is a screening question which clarifies that although it is normal to experience some kind of pain regularly; the questionnaire is aimed at exploring whether the respondent has experienced more pain than they would normally expect. The second element is the generation of both a Pain Severity Score and a Pain Interference Score which allows for the direct evaluation of the impact of pain on function rather than the impact of other health related symptoms on function. Pain interference and pain severity have been identified as two of the four domains whose outcomes should be evaluated in pain trials by the IMMPACT group and the instrument's design and utility are some of the reasons it is recommended by the IMMPACT group<sup>176</sup>.

While the original WBPQ was found to have satisfactory reliability, sensitivity and validity, several items were found to be redundant and standardisation of the scaling strengthened its concurrent validity<sup>175</sup>. The BPI is accepted as the new version of the instrument with demonstrated reliability and content, criterion, and construct validity when self-administered or interviewer administered<sup>96</sup>. Given its robustness in translation, its suitability for use in interview and its wide use in exploring the presence, distribution, severity, treatment and functional impact of pain in HIV/AIDS, the BPI was selected as the primary outcome measure for pain in the present study. As a validated isiXhosa version of the instrument was not available, a full translation process was conducted prior to the initiation of data collection. The results of this translation process are presented in the second half of this chapter. In addition the validity and reliability of the newly translated instrument needed to be established. These results are presented in Chapter 5.

In addition to identifying an appropriate instrument to measure the primary outcome variable of pain, measurement instruments were identified for the collection of information on factors theorised to contribute to pain in PLWHA as identified in Chapter 2 and recommended by the IMMPACT group<sup>176</sup>. These factors include the psychological contributors of depression and post-traumatic stress disorder (PTSD), self-efficacy and health related quality of life.

#### *4.2.2 Depression*

There is a plethora of research reporting on the association between chronic pain and depression with some authors suggesting that 50% of patients with a chronic pain condition will also present with a depressive disorder<sup>132 177</sup>. The relationship between pain and depression appears to be complex and the causality is unclear. The links between pain and depression have also been identified in PLWHA with several of the studies reviewed in Chapter 3, reporting this<sup>73 74 77</sup>. In recognition of the link between pain and depression, the IMMPACT group recommends that clinical research on pain and the effectiveness of clinical interventions on pain should include measures for depression.

One of the most commonly used instruments for the measurement of depression, particularly in chronic pain populations, is the Beck Depression Inventory (BDI)<sup>132 151</sup>. The BDI is a 21-item self-report questionnaire which is designed to measure the severity of symptoms of depression<sup>178</sup>. The instrument can be self-administered or interviewer administered and takes approximately 10 minutes to complete. The instrument has demonstrated good reliability and validity in diagnosing major depressive disorder. However, its sensitivity is weaker in patients with mild symptoms<sup>179</sup>. The BDI is recommended for use by the IMMPACT group and has been used in several previous studies on pain in PLWHA<sup>73 74 100 180-182</sup>.

Several other instruments for the measurement of depression are available including the Centre for Epidemiological Studies Depression Scale (CES-D)<sup>183</sup>; the Zung self-rating depression scale<sup>184</sup>; and the Hospital Anxiety and Depression Scale (HADS)<sup>185</sup>. Both the CES-D and the Zung scales indicate level of depressive symptoms with good levels of reliability and can be used in cross-sectional studies<sup>24</sup>. The HAD has two subscales providing measures of both anxiety and depression with good sensitivity in ill (inpatient) groups. However it appears less robust when used in outpatient populations<sup>186</sup>.

Considering the IMMPACT group recommendations and its use in several previous studies on pain in PLWHA, the BDI was selected for use in the present study both to evaluate the level of depressed mood and to evaluate response to treatment. The BDI is not optimal for clinical use to generate a diagnosis. However, for the purposes of research, cut-off scores have been recommended with a score of > 16 being suggested as indicative of depressive symptoms<sup>132</sup>. The BDI has previously been translated and validated in IsiXhosa and used in studies on this population group<sup>187 188</sup>.

### 4.2.3 *Post-traumatic stress disorder*

Several studies have identified links between post-traumatic stress disorder (PTSD) and pain<sup>116 117 177</sup> with one study reporting people living with pain having a point prevalence of 10% for PTSD compared with 3% in those without pain<sup>177</sup>. Although a history of trauma or the presence of PTSD was not identified as a risk factor for pain in PLWHA by the studies reviewed in Chapter 2, the prevalence and impact of PTSD on pain in PLWHA has been reported elsewhere<sup>116 189</sup>. Over 24 instruments have been developed for the screening of PTSD<sup>190</sup>. However, only one instrument was identified which was developed for use in cross-cultural studies - the Harvard Trauma Questionnaire (HTQ)<sup>191</sup>. The Harvard Trauma Questionnaire (HTQ) was developed to assist clinicians screening refugees for post-traumatic stress disorder (PTSD) in specialist refugee mental health services<sup>191</sup>.

The 30-item questionnaire is designed for use in cross-cultural settings and can be used as a screening instrument, as a clinical assessment tool and in epidemiological and risk factor studies. The HTQ allows for both screening of traumatic events and symptoms of PTSD. However, it does not adhere to the new four factor model of PTSD<sup>192</sup>. In addition, the instrument's performance in detecting PTSD in South African populations has been reported to be poor, however, it should be noted that the instrument was not designed to diagnose PTSD but to identify likelihood of the condition in at risk patients<sup>189 191</sup>.

Despite the noted limitations of the HTQ, the instrument was selected for use in this study as it is quick to administer, was developed for use in cross-cultural studies and has been translated and validated for use in isiXhosa<sup>139 189 193</sup>. For the purposes of this study, where PTSD is being explored as a secondary variable, the instrument should provide sufficient information in order to explore whether likelihood of PTSD is a contributing factor to the presence of pain.

A history of childhood trauma has been recognised as contributing to fatigue in PLWHA<sup>41</sup>. It was hypothesised that a history of childhood trauma may also contribute to pain in PLWHA in a similar manner as recent trauma. Thus, in addition to the traumatic events screened by the HTQ, screening for childhood trauma was also investigated.

The short form of the Childhood Trauma Questionnaire (CTQ-SF) is a 28-item questionnaire which has been found to be a valid and reliable instrument for the screening of maltreatment in diverse clinical and normative populations<sup>194</sup>. The form takes about five minutes to complete and is an effective method of identifying individuals with a history of maltreatment. The questionnaire includes five questions on each of the five clinical scales evaluating physical, sexual and emotional abuse and physical and emotional neglect. A further three questions provide a minimization/denial validity scale which detects underreporting of maltreatment.

While an isiXhosa version of the CTQ-SF is available, no literature describing a well-grounded translation and validation procedure was identified. The instrument has been translated into Swedish and this version had similar psychometric properties of the original American English version<sup>195</sup>. Testing of the original CTQ-SF in different ethnic groups in the USA revealed that there may be cultural differences in the interpretation of some items on the instrument<sup>196-198</sup>. While the instrument was still valid in different cultural groups, the authors advise that it must be used against a background of awareness of the cultural norms of the respondents<sup>198</sup>. Considering the lack of literature regarding the translation and validation procedure used for the isiXhosa version of the CTQ-SF and the cultural challenges identified when translating the instrument into other languages, a rigorous procedure would need to be followed and documented to maintain the semantic equivalence and properties of the questionnaire.

#### 4.2.4 Self-efficacy

Levels of self-efficacy were not assessed nor reported on as risk factors for pain in PLWHA by the studies reviewed in Chapter 3. However, this variable was deemed to be of interest as self-efficacy and pain have been found to interrelate in studies on chronic painful musculoskeletal conditions such as low back pain and fibromyalgia and in studies on chronic painful diseases including rheumatoid arthritis and diabetes<sup>113 122 132 177 199-204</sup>. It has been consistently reported that people with high levels of self-efficacy have lower reported levels of disability than people with the same amount of pain but lower levels of self-efficacy<sup>200 205-208</sup>. For example, women with fibromyalgia and higher levels of self-efficacy, have improved levels of physical activity and decreased symptom distress<sup>203</sup>. In PLWHA increased levels of self-efficacy have been associated with decreased symptom severity and pain and fatigue in a small group of homosexual males following participation in an intervention programme<sup>127</sup>. As the present two-phase study included a peer-led exercise and education intervention programme, an exploration of self-efficacy was deemed relevant based on the relationship between self-efficacy and pain<sup>208</sup> and self-efficacy and self-management in chronic diseases<sup>202 209-211</sup>.

There are several scales which can be used to measure different aspects of health related self-efficacy. The General Self-Efficacy scale<sup>212</sup>, the Pain Self-efficacy questionnaire<sup>213</sup>, and the Self-efficacy for Managing Chronic Disease 6-item Scale<sup>210</sup> were all reviewed for use in this study. The General Self-Efficacy (GSE) scale consists of 10-items which are scored from 1 to 4 with 1 = "not at all true"; 2 = "hardly true", 3 = "moderately true"; 4 = "exactly true"<sup>212</sup>. This instrument has been used to measure self-efficacy in males living with HIV in Australia undertaking a strength training programme<sup>122</sup>. However, the instrument designers emphasise that the scale measures general self-efficacy and that research exploring health related self-efficacy and changes in health related self-efficacy should use instruments designed to evaluate specific health related dimensions<sup>214</sup>.

The Pain Self-efficacy questionnaire (PSEQ) was designed for use in people with chronic pain and has been found to be sensitive to changes in self-efficacy following intervention programmes for chronic pain<sup>213</sup>. As with the GSE the PSEQ consists of 10-items but with respondents indicating on a scale of 0 ("not at all confident") to 6 ("completely confident") their confidence in "doing activities despite the pain". The instrument is specifically targeted towards pain related self-efficacy and in the present study would not be suitable for use by those not reporting pain.

The scale selected for use in the present study was the Self-efficacy for Managing Chronic Disease 6-item Scale (SE-6)<sup>210</sup>. The SE-6 was developed to test the efficacy of chronic disease education programmes. The scale is based on the much longer and more burdensome Chronic Disease Self-efficacy Scales which consist of three sections; the self-management behaviour section (11 questions), general self-efficacy (5 questions) and self-efficacy for achieving outcomes (17 questions)<sup>215</sup>.

The shorter SE-6 is much less burdensome and covers the dimensions of symptom control, role function, emotional functioning and communication with physicians. The scale has a simple semantic structure asking respondents to indicate how confident they are on a NRS from 0 (“not at all confident”) to 10 (“totally confident”) that they can perform certain activities relating to their disease. The scale has been found to be a valid and reliable method of measuring self-efficacy in chronic conditions<sup>216</sup> including AIDS<sup>2</sup>. The chronic disease self-efficacy scale is available in English and Spanish but has not been translated or validated for use by isiXhosa speakers and this will need to be done before incorporation into the study.

#### 4.2.5 *Health related quality of life*

Several of the studies reviewed in Chapter 3, explored the relationship between HRQoL and pain in PLWHA<sup>74 83 85</sup>. Hitchcock et al<sup>86</sup> reported a clear correlation between pain severity and reduced HRQoL in a South African sample while Rosenfeld and colleagues<sup>74</sup> reported reduced HRQoL in those with pain in their sample from the USA. Thus, HRQoL appears to be a critical factor in the prevalence of pain in PLWHA and is a relevant variable to be included in a study on pain in PLWHA.

There are several Health Related Quality of Life (HRQoL) instruments available. Most of these instruments are designed to measure change within a population and are not sufficiently sensitive to measure change in single subjects. As such it is recommended that HRQoL instruments are used in conjunction with other measures of health<sup>217</sup>. In a systematic review of quality of life measurement<sup>218</sup>, the most commonly used instruments were the Medical Outcomes Survey (MOS) SF-36<sup>219</sup>, the Nottingham Health Profile (NHP)<sup>220</sup>, the Sickness Impact Profile (SIP)<sup>221</sup> and the EuroQuol instrument, the EQ-5D life<sup>222</sup>. A review of these instruments revealed that the SF-36 and the EQ-5D had been translated and validated in isiXhosa<sup>223 224</sup>.

The SF-36 contains eight scales of functioning. These are the physical, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health functions. The instrument is scored from 0 to 100, with higher scores indicating better health. The instrument has good reliability and according to some authors the SF-36 is regarded as the “gold standard” against which new HRQoL instruments are compared<sup>217</sup>. The SF-36 has been translated into isiXhosa and was validated in a small sample (21) of people with HIV/AIDS<sup>224</sup>. Although the authors reported acceptable reliability and validity of the translated instrument, there was poor reproducibility in questions referring to vitality, mental health and general health and very poor concurrent validity of the vitality questions. The authors suggest that this was due to the complexity of the questions and that further work needs to be done on the instrument to ensure semantic equivalence<sup>224</sup>. In addition to the concerns raised by the authors, the very small sample makes interpreting these data difficult.

The EQ-5D is a generic, single index measure, which has been used to measure health both for clinical and economic appraisal<sup>222</sup>. The instrument provides a health profile, a weighted health index and a general health status score. The health profile consists of five descriptive domains of function: mobility, self-care, usual activities (work, study, housework, family or leisure), pain/discomfort and anxiety/depression. These domains are assessed by asking respondents to check one of three boxes for each domain indicating no problems, some problems or severe problems.

A weighted summary index can be generated by assigning population weights for each level in the descriptive scale resulting in an EQ-5D index. The instrument includes a 20 cm vertical visual analogue scale (VAS) anchored by “0 - worst imaginable state of health” at the bottom and “100 - best imaginable health” at the top. The general health status score is generated by respondents drawing a line to the point on the VAS which corresponds with their health today and is reported as the EQ VAS<sup>156</sup>. The instrument has good reliability, construct and concurrent validity<sup>222 225</sup>. The EQ-5D has been validated in a wide range of settings in Southern Africa<sup>149 226 227</sup>; has been validated in an urban cohort of Xhosa speakers and has been used in several studies exploring quality of life in urban Xhosa-speaking PLWHA<sup>85 228 229</sup>. The advantages of this instrument include its brevity, its availability in an isiXhosa version and its frequent use in similar populations allowing for comparison between studies. Following review of these instruments, the EQ-5D Xhosa version was selected for use in the present study.

#### 4.2.6 Summary

The instrument selected to measure pain, the primary variable of interest in this study was the Brief Pain Inventory based on its frequent use in previous studies, robustness when translated into other languages, and its applicability to the research questions. The Beck Depression Inventory (BDI) was selected to evaluate the level of depressed mood and response to treatment. To examine the effects of past trauma, the Harvard Trauma Questionnaire and the short form of the Childhood Trauma Questionnaire were selected. In order to evaluate levels of self-efficacy, the Self-efficacy for Managing Chronic Disease 6-item Scale was selected. Finally, to explore health related quality of life, the EQ-5D Xhosa was identified for use.

Once psychometrically sound measurement instruments have been identified for use, translation of instruments not available in the target culture needs to be undertaken. The translation of the measurement instruments identified for use but not available in isiXhosa will now be presented.

## 4.3 Translation of measurement instruments

Three of the instruments selected for use in the present study had not been previously translated into isiXhosa; these were the Brief Pain Inventory (BPI); the Self-efficacy for Managing Chronic Disease 6-item Scale (SE-6) and the Childhood Trauma Questionnaire (CTQ). In this second part of the chapter, the translation of these instruments is described.

### 4.3.1 Aim

To translate the Brief Pain Inventory (BPI), Self-efficacy 6-item scale (SE-6) and the childhood trauma questionnaire (CTQ) into equivalent instruments in isiXhosa.

The specific objectives were to translate the BPI, SE-6 and the CTQ into the BPI-Xhosa, SE-6-Xhosa and the CTQ-Xhosa with

- a) Content equivalence
- b) Semantic equivalence
- c) Technical equivalence

Issues of criterion and conceptual equivalence will be presented in Chapter 5.

### 4.3.2 Procedure

The back translation method described by Beaton and colleagues<sup>138</sup> was used as a basis for the translation procedure with some modification regarding selection of translators to ensure decentring of the process. This method involves five stages: (i) initial translation by two translators; (ii) synthesis of translations through consensus; (iii) back translation by two translators naïve to the original; (iv) expert committee review of the translations and finally (v) testing of the pre-final instrument.

Four translators were recruited. Translators A and B conducted the forward translations while Translators C and D performed the back translations. In order to ensure decentring, all four spoke isiXhosa as their mother tongue but regarded themselves as fully bilingual having received university education in English and subsequently taught or lectured in English. Several authors' recommend that the back translations are performed by first language English speakers; however, in the interests of decentring the back translators selected were bilingual and bicultural<sup>134 138</sup>. This approach has been utilised effectively in the translation of the EQ-5D quality of life measure<sup>135</sup>.

While the back translators' mother tongue was recognised as isiXhosa both translators had studied at university level in English and worked in English environments, and were able to function culturally in both groups. This is a common situation in South Africa with learners often attending school and university in their second or third language. The use of bilingual, bicultural translators enhances the process of translation facilitating the goal of achieving semantic equivalence by increasing the interpretation of cultural-specific nuances and terms <sup>141 147</sup>.

Translators were selected to represent both sexes and across the age spectrum. It is important that the different sexes and age groups are represented when translating instruments into isiXhosa as there are recognised generational differences in language and culture between the sexes and in different age groups<sup>145 148 230</sup>.

Translator A was a male in his 20's with a degree in Occupational Therapy, currently completing a Master's degree. He was employed as a lecturer in Occupational Therapy and as such worked in an English environment. Through his training he was familiar with the concepts being examined. Translator B was a female in her 50's with a qualification in teaching. She was employed in the Department of Education working in trilingual environments. Translator C was a male in his 60's, a retired professor of isiXhosa experienced in teaching in English as well as writing in English for publication. Translator D was a female in her 20's with a degree in information technology experienced in developing websites in English and isiXhosa.

Translators A and B were each provided with a copy of the BPI, CTQ and the SE-6 and asked to translate the instruments into isiXhosa – version A and version B. On completion of the translations the two translators and an observer (the principle investigator) held a consensus meeting to produce a synthesised version of the instruments – version AB (Figure 4-1).

The synthesised version AB of the isiXhosa questionnaire was then given to translators C and D for back translation into English – back translation (BT) C and D. The back translators were not provided with any insight into the instruments nor had access to the original versions. The translators were encouraged to consider the isiXhosa versions of the instruments as the original and not try to decipher what the original English version may have contained. In addition the translators were asked to point out items of confusion, or which were linguistically or culturally uncomfortable or challenging.

On completion of the back translations a committee met to consolidate the versions of the questionnaires and develop a pre-final version of each questionnaire for field testing. The committee consisted of all four translators and the principal investigator of the study.

The committee discussed each line of the translations to ensure that the instruments attained semantic, idiomatic, experiential and conceptual equivalence. Each stage of the process was documented with all comments from translators recorded and every version of the translated documents filed.

Following ethical approval from the Health Sciences Research Ethics Committee of the University of Cape Town (Appendix B; REC Ref 420 2007), the pre-final version of the questionnaires were then field tested on 17 amaXhosa women living with HIV/AIDS who were receiving treatment at the Michael Mapongwana Community Health Centre in Khayelitsha, an urban settlement of Cape Town, South Africa. The questionnaires were administered by a trained female research assistant whose first language is isiXhosa. On completion of each questionnaire (BPI; CTQ and SE-6), participants were asked the following questions in isiXhosa: “Was there any question which was not clear or you did not understand?”, “Are there any words or phrases you didn’t understand?”, and “What do you think the questionnaire was about?”. The research assistant administering the questionnaires then recorded any comments or any difficulties which arose while administering the questionnaire. These comments were then translated by the research assistant into English for evaluation.

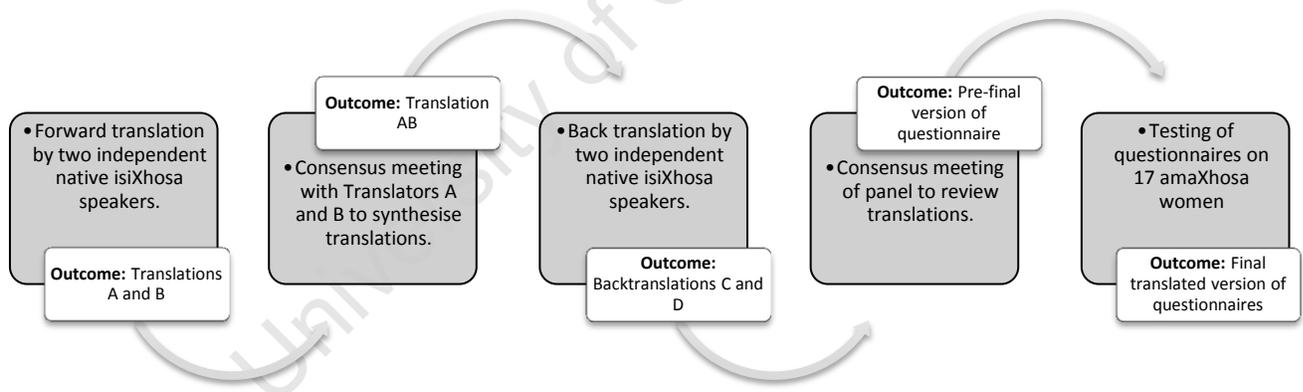


Figure 4-1: Flow chart of the translation process

On completion of testing of the pre-final versions of the questionnaires, modifications were made as necessary and the translated version finalised as the BPI-Xhosa, CTQ-Xhosa and the SE-6-Xhosa. The results of testing for validity and reliability of the newly translated instruments are presented in Chapter 5.

### 4.3.3 Results

The results of the forward and back translations of the three instruments are presented in Appendix C. Challenges to obtaining equivalence in the translated questionnaires identified during forward translation from English into isiXhosa, during back translation from isiXhosa back into English and during field testing of the pre-final version of the instruments were recorded. Following presentation of the challenges identified in the translation, the comments from field testing will be presented.

#### 4.3.3.1 Translation of the BPI

The full results of the forward and back translation of the BPI are presented in Table C-1 and Table C-2 (Appendix C; p. 255 ). Achievement of semantic equivalence of this instrument appeared good; however, specific challenges were noted relating to the achievement of technical equivalence. All the translators identified technical issues with particular reference to the use of scales and terms which were not culturally equivalent.

Questions which required responses using a graded scale from zero to ten as in the BPI were identified as problematic by all four of the translators. The translators all reported that the concept of a graded response is not part of Xhosa culture. Rather, concepts are considered in absolute terms, for example a person is either happy or they are not happy, the concept of being slightly happy is foreign. This difficulty in dealing with the concept of grading responses was identified for all the questions on the BPI as well as for the CTQ and SE-6. The translators expressed concern that responses would be classified at one end of the scale or the other in an "all or none" response.

A second more specific but linked item of difficulty identified in the translation process was the term "average". While there is a Xhosa word for "average" this is regarded as a mathematical construct and the translators reported that the concept of "average pain" might not be interpreted by respondents as intended by the designers of the instrument. Once again this related to the issue that in Xhosa pain is regarded in absolute terms of being present or not present. Similarly the use of percentages to indicate pain relief obtained with medication was identified as potentially problematic. The translators again felt that although a Xhosa word was available that this was regarded as a mathematical construct and applying to relief in this context may prove difficult.

#### 4.3.3.2 Translation of the CTQ

The full results for the translation of the CTQ are presented in Table C-3 and Table C-4 (Appendix C, p. 264). In addition to the issues identified in the translation of the BPI relating to graded scales as described above, additional challenges were faced in the translation of the CTQ with particular reference to sexual terms, language and connotations. In order to maintain semantic equivalence, direct translation was not always maintained but rather correct meaning was the objective.

Particular concerns were raised by the consensus committee around four specific statements in the instrument. The first related to the concept of family identified in: '5. There was someone in my family who helped me feel important or special'. The concept of family in Xhosa culture is broader than the concept of family in Anglo-American culture. On discussion and review of the meaning of the word however, semantic equivalence was felt to have been maintained as the term "family" in both cultures may be used to refer to an extended network of people in caring, trusting relationships.

The second area of concern raised by the consensus committee related to the items with questions of a sexual nature particularly in items 20; 24 and 27 (Table 4-1). There is limited vocabulary on sexual matters in isiXhosa with many sexual matters remaining essentially silent. The consensus committee used colloquial terminology to obtain equivalence where formal Xhosa terms were not available. Translator C (male in his 60's) did not recognise some of these terms, reporting that in his age set such terms were not used. The committee agreed that the translated version had semantic equivalence but emphasised that the terminology used was colloquial and perhaps unique to the urban Cape Town setting and may not be understood by amaXhosa living in rural areas or even in other South African cities.

Table 4-1: Consensus committee comments on specific items from the CTQ-Xhosa

Statement from the CTQ	Consensus committee comments
5. There was someone in my family who helped me feel important or special.	The term used for family in isiXhosa is broader than the Anglo-American concept of family. In Xhosa, the term may refer to people within an extended network of caring, the similarity however was acknowledged that this would refer to trusted relationships.
20. Someone tried to touch me in a sexual way, or tried to make me touch them.	This was very difficult to translate into Xhosa as sexual matters are essentially silent in the language. Touching someone doesn't have any sexual connotation – the statement was worded in such a way that it will imply a sexual connotation.  On back translation, Translator D (a young female with experience in translating materials around sexual harassment) interpreted this wording to mean molestation. She reported that in young urban females the term used in the Xhosa translation was the colloquial wording used for molestation – a term which has no direct isiXhosa equivalent.
24. Someone molested me.	This item was difficult to equate. The terms molestation and rape have different meanings in English but the isiXhosa vocabulary is limited with Translator C (a male in his 60's) reporting that in his age set there was not a word appropriate for rape. The other three translators agreed that the colloquial terms used in the Xhosa version referred to the term molestation and not the more restricted term of rape.
27. I believe that I was sexually abused	Again the limited Xhosa vocabulary for sexual terms and its interpretation was highlighted. Translator C was unfamiliar with this language as in his age set the terms are not used or referred to. The female translators and younger male all felt that the terms used in the Xhosa version were colloquially acceptable and had the correct meaning. The translators all emphasised that these sexual questions must be asked by an interviewer of the same gender as the patient and that age must be considered as conversing on these topics outside of an age set would be very uncomfortable.

#### 4.3.3.3 Translation of the SE-6

The full results for the translation of the SE-6 are presented in Table C-5 and Table C-6 (Appendix C, p. 278). As with the BPI and CTQ, the consensus committee identified the potential difficulty of a zero to ten scale for recording responses and cautioned that distribution of responses should be carefully analysed in the validation process to ensure that respondents do engage with the full spectrum of responses and do not dichotomise responses as is typically done within Xhosa culture. Further issues identified on this instrument revolved around maintaining semantic equivalence and in the use of colloquial terms where terms were not available in formal Xhosa.

In all of the items on the SE-6 the term “interferes with” is used. This term was identified as potentially problematic should the questionnaire be self-administered as depending on the emphasis it could be interpreted as “prohibits”. The committee agreed that the use of the instrument in an interview with a research assistant reading the items out would prevent misunderstanding on this item.

In order to achieve semantic equivalence of the term in item three “physical discomfort or pain”; the Xhosa terms “bodily suffering or pain” were used. The literal back-translation of these terms into English created confusion but when the semantic meaning of the item was discussed it was felt that the Xhosa version was equivalent to the English.

As was identified in the translation of the CTQ, limited formal Xhosa vocabulary for emotional terms was identified as a challenge. To achieve semantic equivalence on the item relating to “emotional distress” the terms “spiritual distress” were used in Xhosa. Once again, although the literal translation was not regarded as accurate, this was felt by the committee to achieve semantic equivalence.

On completion of the translation procedure, the pre-final versions of the questionnaires were field tested.

#### 4.3.3.4 Field testing

Each instrument was read to the participants by the research assistant. Responses were recorded and each participant’s comments regarding the pre-final versions of the questionnaires were noted. The 17 amaXhosa women who participated in the field testing were all HIV+ or living with AIDS [CD4+ 547cells/microL (48 – 8050)] and were attending a community health centre for routine monitoring of their condition. The median age of the participants was 33y (25 – 40); they reported speaking and writing a median of 2 (1 – 4) and 2 (1 – 3) languages respectively. The median number of years spent in school was 11y (6 – 12).

#### *Brief Pain Inventory - Xhosa*

Fourteen of the 17 participants completed the pre-final version of the BPI-Xhosa in full when interviewed. The BPI screens for pain with an initial question which clarifies that it is normal to experience some kind of pain regularly however the questionnaire is aimed at exploring whether the respondent has experienced more pain than they would normally expect. Two participants answered “No” to this initial question and did not complete the full questionnaire.

On the BPI-Xhosa, all 14 participants responded that there were no questions which were unclear or that they did not understand. All participants also responded that there were no words or phrases which were unclear in the pre-final version of the BPI-Xhosa.

Participant responses to the question “What did you think the questionnaire was about?” are presented in Table 4-2. The research assistant recorded that there were no problems with the administration of the questionnaire with participants appearing to understand the questions and no clarification being required.

Table 4-2: Participant perceived meaning of the pre-final BPI-Xhosa

Participant Number	What do you think the questionnaire was about?
1	The question was about my state of health and how painful my parts are.
3	It was about HIV/Aids and pain it gives me.
5	It was about the state of my health and my pain
6	It's about my health condition in everyday of living.
7	It is about my health condition and how do I understand it.
8	I can say is about my health condition and how it is in the past week and how do I feel now.
9	The questions were trying to help me to any problem I have with pain
10	It is about my illness when I am in pain.
11	It is about body parts and how painful is my body.
12	It is about my health condition and how painful is my body.
13	It is about my health condition and how I am if my health condition is not in a good condition or I am not feeling well and have pain.
14	It is about my health condition and how is my health when I have pain.
15	It is about me as I'm living with HIV and how do I feel if I'm suffering from pains.
16	It's about how do I feel about my health.

#### *Childhood Trauma Questionnaire - Xhosa:*

Seventeen participants completed the CTQ when interviewed. Sixteen of the participants felt that the questions were clear. One participant reported difficulty with questions 16, 22 and 28. These questions refer to family and the participant found it difficult to interpret these questions reporting:

*There are some questions I understand and others I didn't understand e.g., number 16, 22 and 28. I can't be sure enough if my life was successful or my parents were supportive because my mother was here in Cape Town and I was at Eastern Cape so I do not know if my mother really loves me or cares or my life as a child was successful because nothing makes sense even now.*

All participants responded that there were no words or phrases which were unclear in the CTQ pre-final. Participant responses to the question “What did you think the questionnaire was about?” are presented in Table 4-3.

Table 4-3: Participant perceived meaning of the pre-final CTQ-Xhosa

Participant Number	What do you think the questionnaire was about?
1	It's about my situation of growing up while I was a child.
2	It's about my life while I was growing up and how I was treated and how do I be
3	It's about my life while I was a child.
4	It's about my child life while I was a child and how do I grow.
5	It's about my health and my way of living while I was a child.
6	It's about my life when growing up.
7	It's about my way of living or how do I grow.
8	It's about my way of living while I was a child.
9	It's about my way of growing up.
10	It's about my life while I was a child and teenager and things that were happening or my way of living while growing.
11	It's about my standard of being cared while I was a child until I become a teenager, how was I cared, was my way of being cared good or bad, for example physical abused.
12	It's about my way of growing of how do I grow up, was it a perfect way.
13	It's about my childhood life on how my family took and close relatives took care of me.
14	It's about my childhood life, on how do I grow up as a child.
15	It's about my childhood life, on how was my life from the time I was a child until I become a teenager.
16	It's about my childhood life, on how did I grow up and what kind of family or parents were taking care of me.
17	It's about my childhood health, on how do I feel about it. And on how I was cared for while growing up and how was my standard of living

The research assistant recorded that four participants struggled with some of the questions or with the questionnaire in general. The research assistant's comments on these four cases are presented in Table 4-4. One participant became very distressed when the questionnaire was administered. This participant was referred to the mental health services for evaluation and support.

Table 4-4: Research assistant's comments on participants who struggled with the pre-final CTQ-Xhosa

Participant Number	Research Assistant's comments
7	She understood every question although she was confused in answering question 16, 22 and 28 instead of giving a number she decided to explain her situation in words first. Most of the time she believed in giving answers before choosing a number.
9	She answered every question although sometimes she got confused by choosing a number which she did not mean and then corrected it. In question number 16 she wanted to know what do I mean by saying "successful/complete life" asking how complete or successful?
10	She answered although she wanted to know what I meant by saying successful life, I explain in this way: It's when your life as a child was perfect or completely satisfying in a way that your parents or family was taking care of you in an acceptable way. For example nurture you in a proper way by giving you food, clothes, and let you learn and so on."
13	She tried to answer the questions although she was crying a lot. So before carrying on asked her if is fine for her to continue with the interview. She agreed to continue but she started to cry again in question number 20. Offered referral and participant referred to mental health services.

*Self-efficacy for managing chronic disease 6-item scale - Xhosa*

Seventeen participants completed the pre-final SE-6-Xhosa when interviewed. All the participants responded that there were no questions which were unclear or that they did not understand. All participants also responded that there were no words or phrases which were unclear in the pre-final version of the SE-6. Participant responses to the question "What did you think the questionnaire was about?" are presented in Table 4-5. The research assistant recorded that there were no problems with the administration of the questionnaire with participants appearing to understand the questions and no clarification required. One participant struggled with answering the questions as she reported feeling very fatigued and struggled to concentrate.

Table 4-5: Participant perceived meaning of the pre-final SE-6-Xhosa

Participant Number	What do you think the questionnaire was about?
1	It's about my standard of living and the pains in my body
2	It is about my health and my behaviour.
3	It is about my health and how do I manage as I'm living with HIV.
4	It's about me and how do I manage my illness.
5	It about my health and the ability of doing things.
6	It's about my everyday life and how do I manage my life while living with HIV.
7	She couldn't explain, she said she has memory problem if she listen and concentrate for a long time.
8	It is about my health maybe if I am not feeling well and what do I usually do if I am
9	It's about helping me with my disease and to see how I do if I am sick, do I usually sleep on the bed or depend to other people.
10	It's about my health and how confident I am in doing things when suffering from pains.
11	It's about a disease and how do I behave if I am suffering from pain.
12	It's about my health and the fact that I can do things on my own without listening from the pain or often consulting doctor or taking tablets.
13	It's about my health and as a sick person how do I handle it. For example, if I am sick do I often use painkillers such as Panado® or a Disprin®
14	It's about my health and how troublesome it is.
15	It's about me as I'm living with this disease and if maybe I kept doing things or I'm not if I'm not feeling well.
16	It's about things that I am confident about it that I can do it for my health.
17	It's about a disease, HIV and how do I manage it and what are the difficulties if I'm not feeling and things that I can't manage.

#### 4.3.4 Discussion

In this section, the process of instrument translation into isiXhosa has been described. Several issues arose in the translation process which had to be addressed with the aim of achieving equivalence of the instruments.

##### 4.3.4.1 Graded responses

The first issue around graded responses was common across all three of the instruments translated and relates to technical equivalence or the method used in the instrument being comparable across cultures. The translators reported that grading of responses such as “somewhat happy” is not a familiar concept in Xhosa culture.

Rather, Xhosa culture and language refers in absolutes, e.g. one is happy or not happy. This difficulty has been identified in the translation of the SF-36 from American English into European languages<sup>231</sup> and in the translation of a mental health battery into Xhosa<sup>139</sup>. Conversely, although this was raised as a concern by the translators of the EQ-5D into Shona, this did not appear to be a problem when the validity of the Shona instrument was examined<sup>135</sup>. The committee agreed that although the grading of responses was essentially a foreign concept in Xhosa, in multicultural communities the approach may be culturally acceptable. This issue will need to be carefully evaluated in the validation of the translated instruments with analysis of distribution of responses for all three instruments. It will also need to be considered anew should the instruments be used in a rural community or in a community with less multicultural contact.

The use of the term “average pain” in the BPI was also identified as challenging. While a linguistic equivalent for the term is available in isiXhosa, it is interpreted as a mathematical concept and is not commonly used in relation to symptoms. This presents a challenge to achieving semantic equivalence. Difficulty with this item has been recognised in other translations of the BPI, in particular in isiZulu, Setswana and Xitsonga with the item being removed from these versions of the instrument<sup>12</sup>. For this isiXhosa version of the instrument, the consensus was that in an urban context participants would understand the meaning of the question and that it should remain subject to validation. However, caution was again expressed regarding the use of the instrument in rural communities with less multicultural exposure.

#### 4.3.4.2 Sexual terminology

Particular challenges were identified in the translation of the CTQ-Xhosa in relation to sexual terminology. Communication about sexual matters is restricted in all cultures through spoken and unspoken norms<sup>232</sup>. In Xhosa culture, sub-groups are recognisable in the use of sexual language with clear distinctions between language use by men and women and different age sets with distinctions between words which are acceptable for use when men are conversing with men, and women with women which are not acceptable for use in mixed gender conversations<sup>233</sup>. Further, the language used by amaXhosa to communicate about sex is recognised to reflect not merely gender identity but also relative social status in the context of the communication. This emphasises the need for careful consideration of social context in both the translation and data collection processes in order to achieve semantic equivalence.

A strength of the translation undertaken for this instrument was a consideration of the language and cultural aspects of sexual terminology. The four translators were selected to represent different social sub-groups (young adult male, young adult female, older adult male and older adult female).

Identifying appropriate words for use in the CTQ which would be both socially acceptable to all the sub-groups and maintain the meaning of the instrument resulted in extended discussion between the translators with recognition of the differences in language use in each sub-group. The final CTQ-Xhosa agreed upon was felt by all the translators to have semantic equivalence.

However, clear guidelines about its appropriate use in a culturally sensitive manner were recommended. These included the need to ensure that the instrument was administered by a researcher of the same cultural sub-group (gender and age) and the need for a private setting. The researcher administering the instrument would also need to be adequately trained in its purpose to ensure correct inflection of the terminology used. All these factors were considered in the field testing of the instrument.

#### 4.3.4.3 Emotional terms

Translation of broader emotional terms such as “mood” and “emotional distress” was challenging as the Anglo-American dichotomous split between physical and emotional states was felt to be foreign to Xhosa culture; challenging the attainment of content equivalence. A similar challenge has been previously identified in the translation of the EQ-5D into Shona with the focus on physical functioning separate from spiritual functioning being problematic<sup>135</sup>. Similarly, this conflict was identified in the translation of a mental health battery into isiXhosa where the Anglo-American propensity to separate emotions from context and separation of mental suffering from physical suffering was foreign<sup>139</sup>.

The challenges expressed by the translation team in the splitting of emotional from physical experiences in Xhosa culture are notable. The original Anglo-American instruments are intended for use in pain research based on a biopsychosocial model (Chapter 1: ). However, as identified by the translation committee, the mind/body split central to Cartesian thinking continues to predominate in the Anglo-American designed instruments. The embodiment of thoughts and emotions, while a relatively new concept in westernised thinking, sits comfortably in the Xhosa world-view.

A difference in worldview between cultures presents a challenge when translating instruments for cross-cultural use, reiterating the benefits of developing instruments intended for cross-cultural use from scratch with equal emphasis on all cultures involved<sup>137</sup>. While such an approach is advantageous and is clearly universal, it results in instruments and data which cannot be compared with previous results. In the present study, the use of a decentred approach with a committee to translate instruments was adopted. This allowed for translation of instruments used in previous studies (facilitating comparison of results), while respecting the world-view of the target culture.

The committee agreed that while the mind/body split evident in the instruments did not 'sit' comfortably in the Xhosa world-view; respondents would understand the meaning of the questions while recognising the foreignness of the concepts.

#### 4.3.4.4 Meaning: spoken versus read language

In the present study, all the instruments were intended to be used in interview form with a research assistant reading the questions to the participants. The committee agreed that this was the best method to adopt to maintain technical equivalence. Although the English versions of the instruments were designed for either interviewer- or self-administration, the interview method of assessment was agreed to be more respectful in Xhosa culture. Further, the translation committee had identified several terms or phrases in the instruments which contained dual meanings, verbal administration of the instruments would minimise confusion on these items.

#### 4.3.4.5 Meaning of the questionnaires

All three of the newly translated instruments appeared to maintain their meaning when participant responses to the question 'What do you think the questionnaire was about?' were evaluated. The majority of responses on the pre-final BPI-Xhosa clearly indicated an understanding that the instrument was exploring pain and its effects suggesting that its meaning was clear. Four of the participants did not identify pain in their response but rather generalised that the questionnaire was asking about their health.

On the CTQ-Xhosa one participant was unable to answer the question but all others indicated an understanding that the instrument was exploring their childhood experiences. In addition several participants identified that the instrument explored both physical environment and emotional factors affecting them as children. Finally the response to what the SE-6-Xhosa was about indicated that there may be some confusion on the term of self-efficacy. The majority of respondents seemed to understand that the instrument was asking how they actually coped with their condition, as opposed to exploring their confidence in their ability to cope. This has not previously been identified as a problem with either the original instrument or the German version<sup>234</sup>. In order to address this possible confusion, guidelines for the research assistant reading the instrument were developed in order to emphasise that the instrument asked about confidence with coping rather than the actual ability to cope.

#### 4.3.4.6 Generalizability

The translation was conducted by first language isiXhosa speakers who regard themselves as bilingual, all of whom live and work in a cosmopolitan urban environment. Further, the instruments were tested on amaXhosa women living with HIV in an urban setting. Therefore the translated instruments may not be readily understood in a rural environment, by men or by unilingual isiXhosa speakers.

In particular, the CTQ-Xhosa with its specific sexual terminology and use of colloquial language may not be interpreted as intended either by males or rural dwellers. Should the instruments be used in different population groups (males or rural groups), piloting would be advisable to ensure semantic equivalence prior to establishing criterion and conceptual equivalence.

#### 4.3.4.7 Strengths and limitations

The strengths of this translation approach include the rigorous procedure followed and the use of translators representing different Xhosa social groups. As discussed earlier, representation of different social groups resulted in comprehensive discussion to ensure that semantic meaning of the instruments was maintained. The use of this approach also highlighted one of the limitations of the procedure followed. Namely, that the instruments were translated specifically for use in Xhosa women and field tested on amaXhosa women living with HIV in an urban area. Equivalence may not be maintained when these instruments are used either with Xhosa men or in rural areas.

## 4.4 Conclusion

In this chapter the selection of psychometrically sound measurement instruments and the translation of instruments into isiXhosa were presented. Instruments were identified to measure pain (Brief Pain Inventory); depression (Beck Depression Inventory), post-traumatic stress disorder (Harvard Trauma Scale) and childhood trauma (Childhood Trauma Questionnaire); self-efficacy (Self-efficacy for managing chronic disease 6-item scale) and health related quality of life (EQ-5D). Three of the instruments (BDI, HTS and EQ-5D) had already been translated into isiXhosa and were found to have equivalence. Although Xhosa versions of the BPI and CTQ were available<sup>173</sup>, no evidence of the translation or validation procedures was found. A Xhosa version of the SE-6 was not available. Translation of the BPI, CTQ and SE-6 was undertaken using a forward-translation, back-translation process with a committee approach for consensus in order to decentre the process and ensure equivalence of the instruments.

Content equivalence of the BPI, CTQ and SE-6 was ensured through the inclusion of both first language English and first language isiXhosa speakers in the translation team who had training in the concepts being explored. The committee approach allowed for the content of each instrument to be discussed and the cultural relevance of phenomena in each culture (original and target culture) to be established.

Semantic equivalence of the BPI, CTQ and SE-6 was safeguarded through the inclusion of both genders and several age groups on the translation committee. The committee was able to explore the meaning of items in the instruments and settle on isiXhosa wording with semantic equivalence which would be largely acceptable across age-groups. With the focus of the present study on isiXhosa women however, the translated versions of the instruments were developed with a specific focus on this group.

Finally technical equivalence of the instruments was discussed by the translation committee. All the selected instruments were designed for self-administration or interviewer administration. To ensure comparable data, the committee recommended that interviewer-administration be used with the instruments to ensure technical equivalence. This method would minimise the risk of confusion from items requiring graded responses and items which in written form may have dual meaning.

In conclusion, six measurement instruments were identified to provide information on pain and its contributing factors in amaXhosa women living with HIV/AIDS. Three of the instruments (BDI, HTS and EQ-5D) were available in isiXhosa. Valid versions of the BDI, CTQ and SE-6 in Xhosa were not available. Translation of these instruments was undertaken and the BDI-Xhosa, CTQ-Xhosa and SE-6-Xhosa with content, semantic and technical equivalence were developed for use in amaXhosa women living in an urban area. The validity and reliability of the instruments will be presented in Chapter 5.



# Chapter 5: Instrumentation – validity and reliability

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## 5.1 Introduction

In Chapter 4, the first steps in the process of developing psychometrically sound measurement instruments for use in isiXhosa patients with HIV and pain were presented. Specifically, the conceptual background to translation issues, and the processes of instrument selection and translation to obtain equivalency were presented. In this chapter, issues of measurement equivalence will be reported on through establishment of the statistical validity and reliability of the newly translated instruments used in the present study.

Validation of measurement instruments can be viewed as a process to determine the degree of confidence which can be placed in inferences made about people based on their scores<sup>152</sup>. Historically the process adopted was based on the “Trinitarian” approach which divided validity into *content*, *criterion* and *construct* validity which were viewed as separate attributes of a measure needing independent determination<sup>235</sup>. However, some authors suggest that this approach is limited as it focuses on the validation of a scale rather than validating the use of a scale within a specific group of people<sup>152</sup>. A shift away from this approach has emerged in the literature with the emphasis now being on the population being studied rather than the instrument itself. As a consequence of this shift in validation theory, some statistical approaches now adopt a hypothesis testing approach, rather than one in which each type of validity is established based on a specific testing procedure. As with the conceptual approach proposed in Chapter 4; an integrated approach to validation can be used where the “Trinitarian” approach is used in establishing validity within a decentred framework where the population to be studied remains the focus.

*Content* validity refers to the non-statistical establishment of the degree to which an instrument explores all areas identified within the literature as being of relevance<sup>152</sup>. For example, in instruments used in the measurement of pain, the IMMPACT group have emphasised the importance of measuring both pain severity and pain interference with function<sup>236</sup>. These issues of content validity were discussed in the selection of measurement instruments in Chapter 3.

*Criterion* validity refers to how well an instrument measures the variable it is designed to measure. Criterion validity can be established through concurrent and predictive validity testing. To establish concurrent validity, the results obtained with a new instrument are correlated with a previously validated measure (although this approach may be invalid if the comparator instrument had a flawed validation process itself). Criterion validity can be further established through predictive testing in longitudinal studies where appropriate.

Finally, *construct* validity refers to whether the instrument correlates with the constructs and hypothesis underpinning its development. Construct validity can be explored using the multitrait-multimethod matrix<sup>237</sup> or through the newer method of confirmatory factor analysis<sup>238</sup>. Confirmatory factor analysis is particularly useful in validating translated instruments as it allows the researcher to confirm that the underlying hypothesis used in the development of the instrument in its original language endures in the translated instrument.

Reliability refers to the amount of error inherent in any measurement. The reliability of an instrument is the extent to which individuals can be distinguished from each other using the scores from the instrument despite the presence of measurement errors<sup>150 152</sup>. As with the definition of validity, there is some conflict in the literature regarding the different types of reliability with terms being given different definitions depending on the context of the research setting and theoretical background of the authors. For example, reproducibility is referred to in some texts as consisting of reliability (measured by correlation) and agreement (measured by absolute agreement), while other authors refer to reproducibility as a component of reliability<sup>150 152 239</sup>.

Several types of reliability have been identified contingent on the factor which may result in error. Error may result from error in the construct of the instrument (*internal consistency*), from the person administering the instrument, from the environment in which the instrument is administered or from the effect of time (all relate to *test-retest reliability*). *Internal consistency* evaluates the uniformity of results from individual items within an instrument<sup>240</sup>. The internal consistency of an instrument can be established by exploring the Cronbach's alpha which is calculated from repeated pairwise correlations of items in the instrument. *Test-retest reliability* can be divided into inter-rater and intra-rater reliability. Inter-rater reliability refers to the consistency of a measure when administered by different individuals. While intra-rater reliability is a form of test-retest reliability in which the degree to which scores are consistent from one testing to the next is established. Both inter- and intra-rater reliability are established through tests of agreement such as correlation co-efficients.

Essentially, when working with translated instruments, evaluation of validity and reliability are performed to explore whether the translated instrument has maintained the structure of the original version presuming that the initial paradigm (e.g. pain) remains constant between cultures. For the purposes of this study, the validity of the newly translated instruments was explored with particular reference to the criterion and construct of the instruments. Further, the internal consistency of these instruments needed to be determined. Finally the reproducibility, in particular the test-retest reliability, of all the instruments used needed to be established to determine and control for possible sources of error.

## 5.2 Aim and objectives

The aim was to determine the validity and reliability of the newly translated instruments (BPI-Xhosa, CTQ-Xhosa, SE-6-Xhosa) and explore the test-retest reliability of all the instrumentation used in the study.

Specific objectives were to determine:

1. Criterion validity of the BPI-Xhosa by examining agreement with previously validated EQ-5D-Xhosa.
2. Construct validity of the BPI-Xhosa by conducting confirmatory factor analysis.
3. Construct validity of the CTQ-Xhosa by multiple correspondence analyses.
4. Construct validity of the SE-6-Xhosa by conducting confirmatory factor analysis.
5. The internal consistency of the BPI-Xhosa, CTQ-Xhosa and the SE-6-Xhos by computing Cronbach's alphas for each instrument
6. The test-retest reliability of all the instruments identified for use in the study (BPI-Xhosa, CTQ-Xhosa, SE-6-Xhosa, EQ-5D-Xhosa, BDI-Xhosa, HTQ-Xhosa) through tests of agreement.

## 5.3 Method

### 5.3.1 Research design

A clinical descriptive analytical study was conducted using a cross-sectional design.

### 5.3.2 Sample

A sample of convenience was utilized. The sample consisted of amaXhosa women living with HIV/AIDS who were attending the HIV/AIDS clinic at a Community Health Centre (CHC) in the resource-poor suburb of Khayelitsha in Cape Town. Women attending the CHC for routine monitoring of their condition at the HIV clinic were invited to take part in a study exploring quality of life in amaXhosa women living with HIV/AIDS. Inclusion criteria comprised being female, a first language isiXhosa speaker, being HIV positive (at any clinical stage) and between 18 and 40 years of age. Exclusion criteria included having a moderate to severe intellectual disability or cognitive impairment restricting ability to participate in an interview. As information was gathered by interview, literacy was not a requirement. The target sample size was a minimum of 100 participants as this is the smallest recommended sample size when determining the validity of an instrument using factor analysis<sup>12</sup>.

### 5.3.3 Procedure

Ethical approval was obtained from both the Faculty of Health Sciences Health Ethics Committee of the University of Cape Town (REC Ref: 420 2007) and the Province of the Western Cape Department of Health (Ref: 19/18/RP12/2009) (Appendix B). Patients, who expressed an interest in participating in a study exploring quality of life in amaXhosa women living with HIV/AIDS, were provided with an information sheet (Appendix D). Patients who wished to participate in the study were then given the opportunity to have any questions answered by the research assistant prior to completing informed consent (Appendix D). Participants were subsequently interviewed by the research assistant in a private setting. Data was collected using a demographic questionnaire; the newly translated versions of the BPI-Xhosa, CTQ-Xhosa and the SE-6-Xhosa; and the previously translated and validated isiXhosa versions of the EQ-5D, BDI and HTQ (Appendix E).

For the test-retest component of the study to examine reliability of the instruments, 10% of the participants were asked to return for a second interview. On completion of their routine clinic consultation, the participants in this part of the study were interviewed by the research assistant a second time. Repeat measures of all instruments were obtained (BPI-Xhosa, CTQ-Xhosa, SE-6-Xhosa, EQ-5D-Xhosa, BDI-Xhosa, HTQ-Xhosa). In order to establish inter-observer reliability, the primary investigator randomly drew ten files and recorded demographic data independently.

### 5.3.4 Data analysis

#### 5.3.4.1 Scoring of instruments

The BPI-Xhosa was used to generate scores for pain severity (pain severity scale – PSS) and for pain interference with function (pain interference scale – PIS) as described by the authors of the instrument<sup>96,241</sup>. Scores from the CTQ-Xhosa were used to calculate mean total scores and scores for each of the subscales of emotional neglect, physical neglect, emotional abuse, physical abuse and sexual abuse using the scoring described by the authors<sup>194</sup>. A single score was generated from the SE-6-Xhosa using the formula described by the authors<sup>242</sup>. The EQ-5D was used to generate three scores, the frequency distributions for the five descriptive domains, a single EQ-5D index based on the five domains and an EQ-VAS. The EQ-5D index was calculated using the York A1 tariff set derived from a population survey conducted in the United Kingdom<sup>243</sup>. Scores derived using the York A1 tariff set range from 1.0 indicating no problems in any of the five dimensions on the descriptive domains to -0.594 indicating severe problems in all five dimensions<sup>244</sup>. The Harvard Trauma Questionnaire and the Beck Depression Inventory were scored using the guidelines provided by the authors of the instruments<sup>179,191</sup>.

#### 5.3.4.2 Validity

Criterion validity was established by determining concurrent agreement with previously validated isiXhosa instruments. Agreement of the BPI-Xhosa was explored by comparing pain severity scores with pain scores on the validated EQ-5D-Xhosa using Spearman's correlations. Agreement of the SE-6-Xhosa was explored by comparing scores to the EQ VAS from the EQ-5D-Xhosa.

Confirmatory factor analysis was performed to explore construct validity of the BPI-Xhosa. Using the approach adopted by the designers of the instrument, confirmatory factor analysis with Varimax rotation was conducted on the BPI-Xhosa to explore whether the original hypothesis of a two-factor structure<sup>245</sup> or whether the newer hypothesis of a three-factor structure of the instrument<sup>241</sup> was maintained in the isiXhosa version. Factors with eigenvalues of greater than one were kept. The percentage of variance explained by each of the factors was determined to explore the extent to which each factor explained the variance in the data. Factor loadings were explored to determine suitability for groupings, with loading of  $> 0.55$  regarded as meaningful<sup>12 146 169 171 194 198</sup>.

Multiple correspondence analysis (the equivalent of confirmatory factor analysis for nominal categorical data) was performed on the CTQ-Xhosa to determine whether the translated instrument maintained the five factor structure of the original version<sup>198</sup>. Confirmatory factor analysis was conducted on the SE-6-Xhosa to determine factor structure as described by the German translators of the instrument<sup>234</sup>.

#### 5.3.4.3 Reliability

Reliability of the newly translated instruments was determined through evaluation of internal consistency by computing Cronbach's alphas for each of the newly translated instruments (including any subscales of the instrument). Alpha values for each subscale were recalculated with individual items deleted in order to explore the contribution each item made to the underlying construct of the subscale. A reliability coefficient of 0.7 for the Cronbach alpha was regarded as acceptable internal consistency for the subscale under consideration<sup>12</sup>. It is expected that the alpha value will decrease with the removal of an item from the subscale; a rise in the alpha value with the removal of an item indicates that the item compromises the underlying construct of the subscale and should be removed.

Test-retest reliability of all the instruments was explored through tests of agreement. Pearson's correlation coefficients were calculated to determine agreement between repeat measures.

## 5.4 Results

Summary results of the sample are presented first (full results of the sample are presented in Chapter 6). The validity and reliability of the newly translated instruments will then be presented. Finally the test-retest reliability of all the instruments will be presented.

### 5.4.1 Summary results

Two hundred and twenty-nine amaXhosa women attending a CHC in the resource poor community of Khayelitsha in Cape Town participated in the study. Socio-demographic characteristics of the sample are presented in Table 5-1. The mean age of the respondents was  $30.73 \pm 4y$  (range 19 – 40). All were first language isiXhosa speakers. All participants were HIV+ with 58% of the participants classified as having AIDS (WHO Clinical Stage III or IV).

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Table 5-1: Socio-demographic characteristics of the sample (N = 229)

	Frequency (%)	Mean $\pm$ SD	Median (Range)
<b>Age (y)</b>		30.73 $\pm$ 5	30 (19 – 40)
<b>Languages</b>			
Number of spoken languages		2.28 $\pm$ 1	2 (1 – 5)
Number of written languages		2.03 $\pm$ 1	2 (0 – 4)
<b>Employment Status</b>			
Unemployed	150 (66)		
In formal employment	38 (17)		
Homemaker/domestic worker	27 (12)		
Self-employed	3 (1)		
Working or has worked in health services or social welfare	5 (2)		
Learner	5 (2)		
Missing	1 (0.5)		
<b>Educational Level</b>			
Number of years in school		10.37 $\pm$ 2	11 (3 – 12)
Primary ( $\leq$ Grade 7)	18 (8)		
Grade 8 - 10	82 (36)		
Grade 11	62 (27)		
Grade 12	44 (19)		
Diploma or equivalent	21 (9)		
Missing	2 (1)		
<b>Marital Status</b>			
Single	133 (58)		
Partner	47 (21)		
Married	36 (16)		
Separated	6 (3)		
Divorced	2 (1)		
Widowed	5 (2)		

### 5.4.1.1 Pain

Pain was measured using the BPI-Xhosa. As mentioned in Section 4.2.1 Measurement of pain (p. 67), the BPI-Xhosa includes a screening question which clarifies that although it is normal to experience some kind of pain regularly; the questionnaire is aimed at exploring whether the respondent has experienced more pain than that they would normally expect. Only participants responding “yes” to this initial question complete the entire instrument. Of the 229 participants in the study, 170 responded “yes” to the screening question and completed the BPI-Xhosa. The summary responses for the BPI-Xhosa are presented in Table 5-2. Participants reported a mean of  $2.42 \pm 1.21$  different pains at the time of interview. The mean pain severity score (PSS) was  $5.06 \pm 1.57$  and the mean pain interference score (PIS) was  $6.39 \pm 1.96$ .

Table 5-2: Summary responses on the BPI-Xhosa (n = 170)

	Mean $\pm$ SD	Median (Range)
<b>Pain Severity Score</b>	5.06 $\pm$ 1.57	4.25 (2 – 9)
Worst pain	7.52 $\pm$ 1.73	8 (3 – 10)
Least pain	4.65 $\pm$ 1.73	5 (1 – 10)
Average pain	3.93 $\pm$ 1.86	4 (0 – 10)
Pain now	4.14 $\pm$ 2.69	4 (0 – 10)
<b>Pain Interference Score</b>	6.39 $\pm$ 1.96	5.57 (0 – 10)
Pain interference with activity	6.52 $\pm$ 2.56	7 (0 – 10)
Pain interference with mood	6.63 $\pm$ 2.76	7 (0 – 10)
Pain interference with ability to walk	6.18 $\pm$ 2.77	7 (0 – 10)
Pain interference with ability to do normal work	6.11 $\pm$ 2.68	6 (0 – 10)
Pain interference with relations with other people	5.89 $\pm$ 2.96	5.5 (0 – 10)
Pain interference with sleep	6.56 $\pm$ 2.78	7 (0 – 10)
Pain interference with enjoyment of life	7.07 $\pm$ 2.46	8 (1 – 10)

*Scale of 0 – 10; 0 = no pain/does not interfere and 10 = pain as bad as you can imagine/completely interferes*

### 5.4.1.2 Childhood trauma

All 229 of the participants completed the Childhood Trauma Questionnaire – Xhosa (CTQ-Xhosa). One hundred and sixteen of these were classified as valid profiles, 57 had some minimization or denial while 56 were classified as questionable profiles. The classification of “questionable profile” is a reflection that responses to the questionnaire were not consistent. These profiles were not included in the analysis.

The results of the remaining 173 profiles are presented in Table 5-3. The mean score on the CTQ-Xhosa was 49.42 ± 11 (median 47; range 33 – 99) for the total sample. The mean score for the valid profiles was 51.11 ± 11 (median 48; range 33 - 76). The CTQ provides information on emotional neglect, physical neglect, emotional abuse, physical abuse and sexual abuse.

Table 5-3: CTQ-Xhosa Valid Profiles (n = 173)

	Count	%
<b>Emotional Neglect</b>		
None or Minimal	88	50.86
Low to Moderate	63	36.42
Moderate to Severe	13	7.51
Severe to Extreme	9	5.20
<b>Physical Neglect</b>		
None or Minimal	53	30.63
Low to Moderate	64	36.99
Moderate to Severe	36	20.81
Severe to Extreme	20	11.56
<b>Emotional Abuse</b>		
None or Minimal	131	75.72
Low to Moderate	33	19.08
Moderate to Severe	7	4.05
Severe to Extreme	2	1.16
<b>Physical Abuse</b>		
None or Minimal	125	72.25
Low to Moderate	14	8.09
Moderate to Severe	13	7.51
Severe to Extreme	21	12.14
<b>Sexual Abuse</b>		
None or Minimal	121	69.94
Low to Moderate	15	8.67
Moderate to Severe	21	12.14
Severe to Extreme	16	9.25

*Categories rated on a four-point ordinal scale ranging from "none or minimal" to "severe to extreme"*

### 5.4.1.3 Self-efficacy

All 229 participants completed the Self-efficacy for Managing Chronic Disease 6-item Scale in Xhosa (SE-6-Xhosa). The SE-6-Xhosa generates a single score for self-efficacy between one (low levels of self-efficacy) and 10. The score is calculated as the mean of the six items on the scale. Summary results are presented in Table 5-4. The mean self-efficacy scores for the participants was  $6.6 \pm 1.59$ .

Table 5-4: Summary responses on the SE-6-Xhosa (N = 229)

	Mean $\pm$ SD	Median (Range)
<b>Self-efficacy Score</b>	6.60 $\pm$ 1.6	6.66 (3 – 10)
How confident are you that you can keep the <b>fatigue</b> caused by your disease from interfering with the things you want to do?	6.55 $\pm$ 2.37	7 (1 – 10)
How confident are you that you can keep the <b>pain</b> caused by your disease from interfering with the things you want to do?	5.78 $\pm$ 2.7	5 (1 – 10)
How confident are you that you can keep the <b>emotional distress</b> caused by your disease from interfering with the things you want to do?	6.55 $\pm$ 2.4	7 (1 – 10)
How confident are you that you can keep any <b>other symptoms or health problems</b> you have from interfering with the things you want to do?	6.43 $\pm$ 2.5	7 (1 – 10)
How confident are you that you can do the different <b>tasks and activities</b> needed to manage your health condition so as to reduce your need to see a doctor?	7.05 $\pm$ 2.4	7 (1 – 10)
How confident are you that you can do <b>things other than just taking medication</b> to reduce how much your illness affects your everyday life?	7.26 $\pm$ 1.6	8 (1 – 10)

Scale of 0 – 10; 0 = not at all confident, 10 = totally confident

### 5.4.1.4 Health related quality of life

Health related quality of life was obtained from all 229 of the participants using the EQ-5D-Xhosa. The results from the instrument are presented as the health profile (consisting of five domains of function: mobility, self-care, usual activities (work, study, housework, family or leisure), the weighted health index (EQ-5D index) and a general health status score (EQ VAS ranked from 0 -100). The health profile of the sample is presented in Table 5-5. The mean EQ-5D index for the sample was  $0.82 \pm 0.18$  (median 0.88; range 0.09 – 1.00). EQ VAS for the sample was  $73.56 \pm 18.58$  (median 80; range 10 – 100).

Table 5-5: Health profile as reported on EQ-5D (N = 229)

	Count	%
<b>Mobility</b>		
No problems	41	18
Some problems	188	82
Confined to bed	0	0
<b>Self-care</b>		
No problems	216	94
Some problems	13	6
Unable to wash or dress self	0	0
<b>Usual activities</b>		
No problems	189	83
Some problems	37	16
Unable to perform	3	1
<b>Pain/Discomfort</b>		
No pain or discomfort	75	33
Moderate pain or discomfort	135	59
Extreme pain or discomfort	19	8
<b>Anxiety/Depression</b>		
Not anxious or depressed	143	62
Moderately anxious or depressed	73	32
Extremely anxious or depressed	13	6

#### 5.4.1.5 Trauma

The Harvard Trauma Questionnaire Xhosa (HTQ-X) was used to explore likelihood of Post-Traumatic Stress Disorder (PTSD). The instrument produces a total score indicating impact of previous trauma while the mean of the first 16 items on the instrument indicates specific likelihood for PTSD. Scores of  $\geq 2$  are interpreted as indicating an increased likelihood of PTSD. Two hundred and fourteen participants completed this instrument. The 15 participants who did not complete this instrument were unable to do so due to time constraints and the need to obtain medication from the pharmacy prior to the clinic closing. The median score for the 214 respondents was  $< 2$ , 55% of respondents had scores of  $< 2$  for the total score and 52.8% having scores of  $< 2$  for the PTSD Score (Table 5-6).

Table 5-6: Scores from the HTQ (n = 214)

	Mean $\pm$ SD	Median (Range)
<b>Harvard Trauma Scale (0 – 4)</b>		
Total Score	1.69 $\pm$ 1.09	1.73 (0 – 3.83)
PTSD Score	1.74 $\pm$ 1.12	1.81 (0 – 3.75)

#### 5.4.1.6 Depression

The Beck Depression Inventory generates a score which can be used as an indicator of risk for depression. A score of  $> 13$  is regarded as indicative of depressive symptoms<sup>246</sup>. One participant did not complete the BDI due to time restrictions. The sample size was thus 228. The mean score on the BDI was  $16.96 \pm 10.4$  (median 15; range 1 – 43). One hundred and twenty-five (55%) of the participants had scores of  $>13$ .

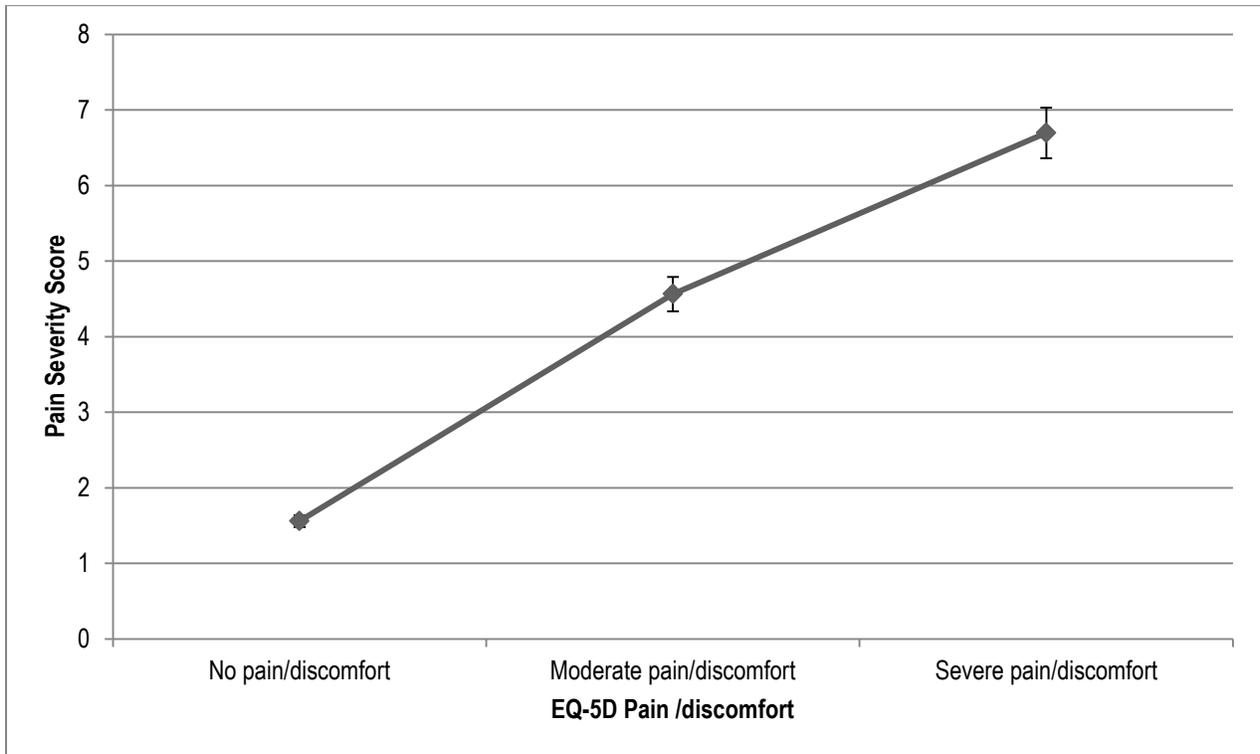
### 5.4.2 *Validity and reliability of newly translated instruments*

The validity and reliability of each of the newly translated instruments will be presented for the BPI-Xhosa, the CTQ-Xhosa and the SE-6-Xhosa respectively.

#### 5.4.2.1 BPI-Xhosa

In order to examine convergent validity, the pain severity scores on the BPI-Xhosa were compared to the pain scores on the EQ-5D-Xhosa which has been previously validated for use in this population. Participants were grouped according to responses on the EQ-5D domain for pain into three groups, no pain/discomfort, moderate pain/discomfort and severe pain/discomfort.

The mean PSS from the BPI-Xhosa of participants when grouped according to the EQ-5D pain domains were significantly different when analysed using a one-way ANOVA [ $F_{(2-185)} = 55.67$ ;  $p < 0.01$ ] (Figure 5-1). Using Tukey's post-hoc test, there was a significant difference in mean PSS between women with no pain/discomfort and moderate/pain discomfort ( $p < 0.01$ ); no pain and severe pain/discomfort ( $p < 0.01$ ) and between women with moderate pain/discomfort and severe pain/discomfort ( $p < 0.01$ ).



*Vertical bars denote 95% CI*

Figure 5-1: One-way ANOVA comparing mean PSS according to EQ-5D pain/discomfort groups

Confirmatory factor analysis revealed a two-factor structure for the BPI-Xhosa. All the pain severity items loaded on one factor and all the pain interference items loaded on the second factor (Figure 5-2). The eigenvalue for pain interference was 4.23, and for pain severity was 1.80 (Table 5-7). The factors explained a combined variance of 54.79%. Pain interference explained 38.46% of the variance while pain severity explained 16.33% of the variance.

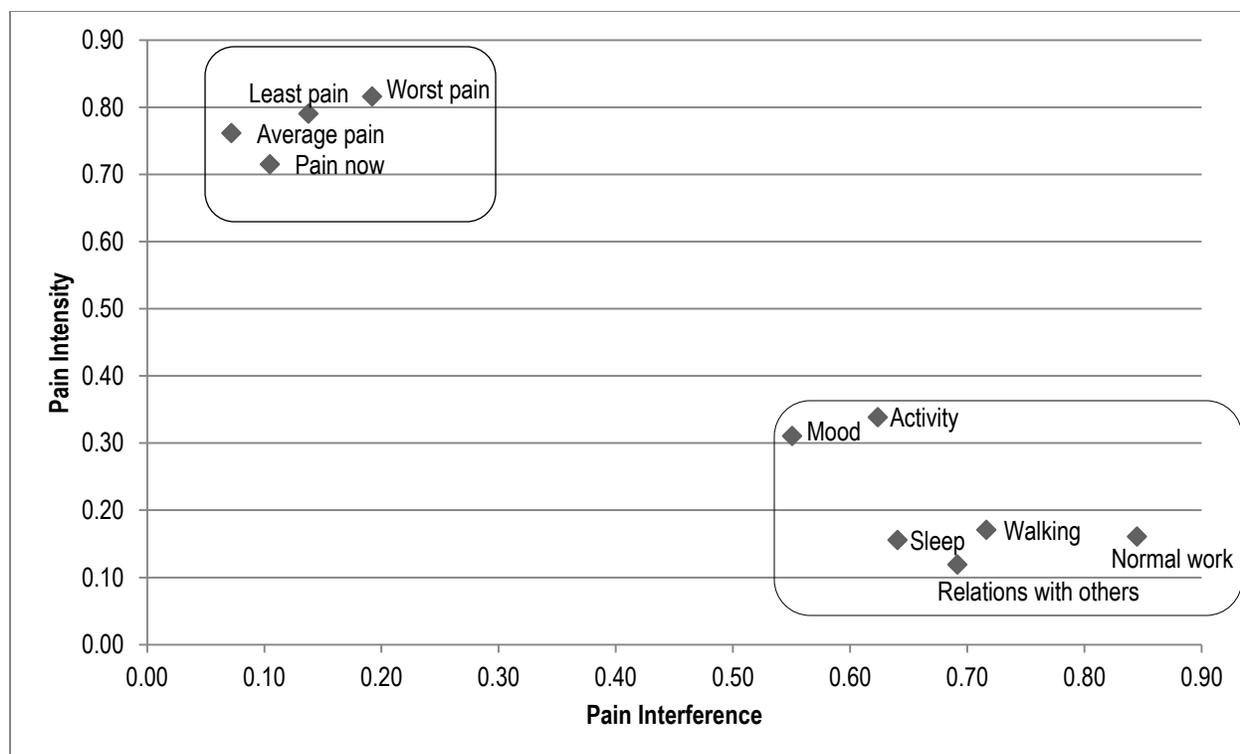


Figure 5-2: Factor loading of the BPI-Xhosa

Table 5-7: Factor loadings for principle components on the BPI-Xhosa (bold factors > 0.55)

Variable	Pain Interference	Pain Severity
<b>Pain Severity Items:</b>		
Worst pain	0.21	<b>0.81</b>
Least pain	0.15	<b>0.79</b>
Average pain	0.08	<b>0.76</b>
Pain now	0.12	<b>0.71</b>
<b>Pain Interference Items:</b>		
Pain interference with activity	<b>0.63</b>	0.33
Pain interference with mood	<b>0.56</b>	0.30
Pain interference with ability to walk	<b>0.72</b>	0.16
Pain interference with ability to do normal work	<b>0.85</b>	0.15
Pain interference with relations with other people	<b>0.69</b>	0.11
Pain interference with sleep	<b>0.64</b>	0.15
Pain interference with enjoyment of life	<b>0.67</b>	-0.08

Internal consistency of the BPI-Xhosa was analysed by calculating reliability. A reliability coefficient of 0.7 for the Cronbach alpha is regarded as acceptable internal consistency for the subscale under consideration<sup>241</sup>. The pain severity subscale had an alpha of 0.77, the pain interference subscale an alpha of 0.83. Omission of items in each of the subscales did not affect the underlying construct of the subscales (Table 5-8).

Table 5-8: Item analysis alpha values with item deletion for the BPI-Xhosa

	Alpha value	Alpha value if item deleted
<b>Pain Severity</b>	<b>0.77</b>	
Worst pain		0.68
Least pain		0.70
Average pain		0.70
Pain now		0.79
<b>Pain Interference</b>	<b>0.83</b>	
Pain interference with activity		0.80
Pain interference with mood		0.81
Pain interference with ability to walk		0.80
Pain interference with ability to do normal work		0.77
Pain interference with relations with other people		0.80
Pain interference with sleep		0.81
Pain interference with enjoyment of life		0.82

In order to evaluate difficulty with the instrument, the number of respondents who reported their pain now, least pain or average pain as worse than the worst pain was determined. Thirteen (8.67%) of the participants reported their pain now, least pain or average pain as worse than their worst pain. There was no change in the convergent validity, factor structure or internal consistency of the instrument when these 13 participants were excluded from the calculations.

#### 5.4.2.2 CTQ-Xhosa

The construct validity and internal consistency of the instrument were computed. A five factor structure (eigenvalues of > 1 were accepted) was obtained. The five factors explained 58.88% of the variance. Exploration of factor loading revealed poor loading of items in the physical neglect factor (Table 5-9).

Table 5-9: Factor loadings for the CTQ-Xhosa

	EN	SA	PA	PN	EA
<b>Physical Neglect (PN)</b>					
Item 1	0.02	-0.01	-0.01	<b>0.70</b>	0.06
Item 4	0.20	0.21	0.23	0.30	0.34
Item 6	0.35	0.12	0.19	0.09	<b>0.51</b>
Item 26	<b>0.61</b>	0.07	0.15	-0.07	0.41
Item 2	0.33	-0.07	0.16	-0.37	0.37
<b>Emotional Abuse (EA)</b>					
Item 3	0.07	0.00	0.27	0.19	<b>0.65</b>
Item 14	0.16	0.07	0.26	0.01	<b>0.70</b>
Item 18	0.20	0.16	<b>0.60</b>	0.24	0.36
Item 25	0.13	<b>0.45</b>	0.37	0.28	<b>0.48</b>
Item 8	0.05	0.10	0.09	-0.09	<b>0.77</b>
<b>Physical Abuse (PA)</b>					
Item 9	-0.02	0.04	<b>0.82</b>	0.07	0.18
Item 11	0.09	0.10	<b>0.77</b>	-0.14	0.10
Item 12	0.26	0.00	<b>0.68</b>	0.10	0.13
Item 15	0.22	0.19	<b>0.71</b>	0.02	0.25
Item 17	0.10	0.17	<b>0.58</b>	-0.27	0.32
<b>Sexual Abuse (SA)</b>					
Item 20	-0.05	<b>0.70</b>	0.08	-0.16	0.11
Item 21	-0.03	<b>0.70</b>	0.20	0.22	0.05
Item 23	0.15	<b>0.75</b>	-0.00	0.02	0.09
Item 24	0.05	<b>0.82</b>	0.12	-0.03	0.00
Item 27	0.20	<b>0.83</b>	0.04	0.05	0.08
<b>Emotional Neglect (EN)</b>					
Item 5	<b>0.71</b>	0.06	0.07	-0.20	-0.11
Item 7	<b>0.65</b>	0.22	0.12	-0.09	0.39
Item 13	<b>0.68</b>	-0.01	0.06	0.40	0.21
Item 19	<b>0.71</b>	0.10	0.30	0.32	0.12
Item 28	<b>0.51</b>	0.11	0.25	0.07	<b>0.48</b>

*(bold values > 0.45)*

Removal of the physical neglect factor resulted in a four factor structure with eigenvalues > 1 which explained 59.76% of the variance. Exploration of factor loading revealed good loading in the factors for physical abuse, sexual abuse and emotional neglect (loading of > 0.60) (Table 5-10). Weaker factor loading was evident in the factor for emotional abuse.

Table 5-10: Factor loading for the CTQ-Xhosa after removal of poorly loaded items

	PA	SA	EN	EA
<b>Emotional Abuse (EA)</b>				
Item 3	0.36	0.03	0.23	<b>0.59</b>
Item 14	0.38	0.09	0.25	<b>0.63</b>
Item 18	<b>0.70</b>	0.13	0.31	0.16
Item 25	0.48	0.47	0.30	0.26
Item 8	0.24	0.09	0.18	<b>0.59</b>
<b>Physical Abuse (PA)</b>				
Item 9	<b>0.82</b>	0.04	-0.05	0.06
Item 11	<b>0.71</b>	0.11	-0.04	0.22
Item 12	<b>0.63</b>	-0.01	0.30	0.08
Item 15	<b>0.77</b>	0.14	0.26	0.12
Item 17	<b>0.58</b>	0.14	0.02	0.38
<b>Sexual Abuse (SA)</b>				
Item 20	0.08	<b>0.72</b>	-0.09	0.17
Item 21	0.31	<b>0.64</b>	0.15	-0.25
Item 23	-0.02	<b>0.79</b>	0.03	0.10
Item 24	0.06	<b>0.84</b>	0.02	0.06
Item 27	0.09	<b>0.83</b>	0.26	-0.04
<b>Emotional Neglect (EN)</b>				
Item 5	-0.01	0.05	<b>0.63</b>	-0.08
Item 7	0.22	0.19	<b>0.66</b>	0.30
Item 13	0.08	-0.00	<b>0.74</b>	0.26
Item 19	0.25	0.07	<b>0.66</b>	0.28
Item 28	0.35	0.11	<b>0.54</b>	-0.55

(bold values > 0.5)

Internal consistency of the CTQ-Xhosa was analysed by calculating reliability. The Cronbach alpha for the full instrument with a five factor structure was 0.42. The Cronbach alpha for the instrument with the factor for physical neglect removed was 0.69. The alpha value for each of the subscales was acceptable (> 0.7). Subsequently the alpha values (with removal of the factor for physical neglect) were calculated when individual items were deleted in order to explore the contribution each item made to the underlying construct of the subscale. Omission of items in each of the subscales did not significantly increase the reliability of the instrument (Table 5-11).

Table 5-11: Item analysis alpha values with item deletion for the CTQ-Xhosa

	Alpha value	Alpha value if item deleted
<b>Emotional Abuse</b>	<b>0.79</b>	
Item 3		0.76
Item 14		0.75
Item 18		0.75
Item 25		0.78
Item 8		0.74
<b>Physical Abuse</b>	<b>0.81</b>	
Item 9		0.77
Item 11		0.76
Item 12		0.81
Item 15		0.75
Item 17		0.80
<b>Sexual Abuse</b>	<b>0.82</b>	
Item 20		0.82
Item 21		0.80
Item 23		0.78
Item 24		0.76
Item 27		0.74
<b>Emotional Neglect</b>	<b>0.79</b>	
Item 5		0.81
Item 7		0.73
Item 13		0.75
Item 19		0.71
Item 28		0.73

#### 5.4.2.3 SE-6-Xhosa

The SE-6-Xhosa was completed by all 229 participants. Convergent validity was explored by comparing self-efficacy scores with the EQ VAS. There was a significant positive correlation between the SE-6-Xhosa scores and the EQ VAS using a Spearman's rank order correlation ( $r_s = 0.32$ ;  $p < 0.05$ ). Confirmatory factor analysis revealed that the instrument had a one-dimensional structure which explained 44% of the variance of the instrument.

Internal consistency of the SE-6-Xhosa was analysed by calculating reliability. The Cronbach alpha for the instrument was 0.74. As presented in Table 5-12, omission of items did not increase the reliability of the instrument.

Table 5-12: Item analysis alpha values with item deletion for the SE-6-Xhosa

Item	Alpha value	Alpha value if item deleted
<b>SE-6-Xhosa</b>	<b>0.74</b>	
SE-6 - fatigue		0.74
SE-6 - pain		0.68
SE-6 - emotional distress		0.71
SE-6 - other symptoms/health problems		0.72
SE-6 - tasks to manage health		0.68
SE-6 - things other than medicines to manage health		0.71

#### 5.4.3 *Test-retest reliability*

Test-retest reliability was explored for intra- and inter-observer reliability where possible.

##### 5.4.3.1 Sample

There were 31 participants in the study to explore test-retest reliability. The mean age of the participants was  $33.29 \pm 5.59$  years. Fifteen of the participants were single, 13 were living with a partner and three were widowed. All were first language isiXhosa speakers reporting that they could speak, read and write in Xhosa. In addition, all but three could speak English, seven could speak Zulu and two could speak Sesotho.

In the demographic questionnaire, there were missing data relating to information at diagnosis (stage and CD4+ count) but all other information was available and recorded. Demographic data collected by the PI from the medical files was compared with that collected by the research assistant to explore inter-observer reliability. Data sheets completed by the PI and the researcher assistant fully corresponded in all the cases. Results for intra-observer test-retest reliability are presented for each instrument.

### 5.4.3.2 BPI-Xhosa

Seventeen participants who had reported pain on the first interview returned for a second interview. There was absolute agreement on the item relating to the presence of pain in the previous week. The body chart depicted the same areas of pain reported, with the exception of two participants. One indicated abdominal pain on the first interview and not the second, the second indicated only foot and flank pain on the first chart but foot, flank, thorax, arm and leg pain on the second chart.

Scores contributing to the pain severity subscale of the BPI were compared. The pain severity scores (PSS) had good agreement with Pearson's  $r = 0.86$  ( $n = 17$ ;  $p < 0.05$ ) (Figure 5-3).

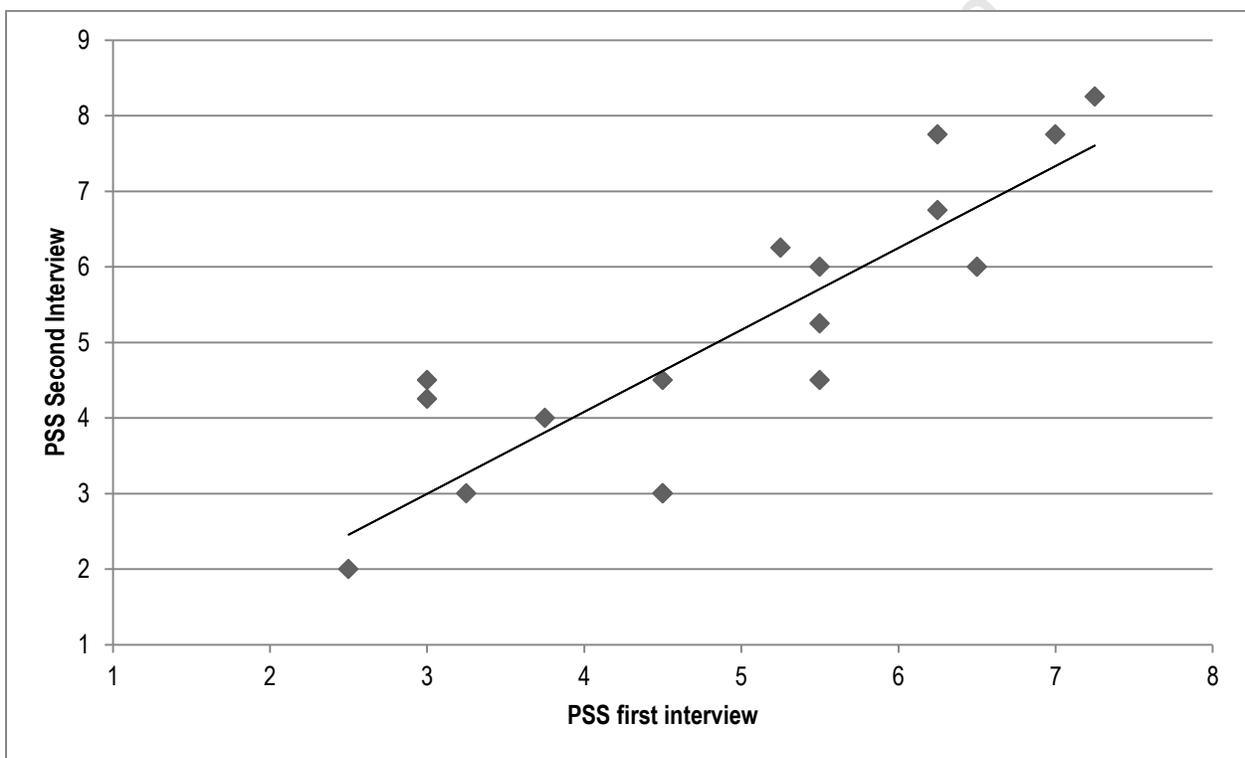


Figure 5-3: Scatterplot of Pain Severity Scores at first and second interview [Pearson's  $r = 0.86$  ( $p < 0.05$ ) ( $n = 17$ )]

Agreement between scores on the pain interference score (PIS) of the BPI was then explored. There was good agreement between scores for the PIS (Pearson's  $r = 0.79$ ,  $n = 17$ ;  $p < 0.05$ ) (Figure 5-4).

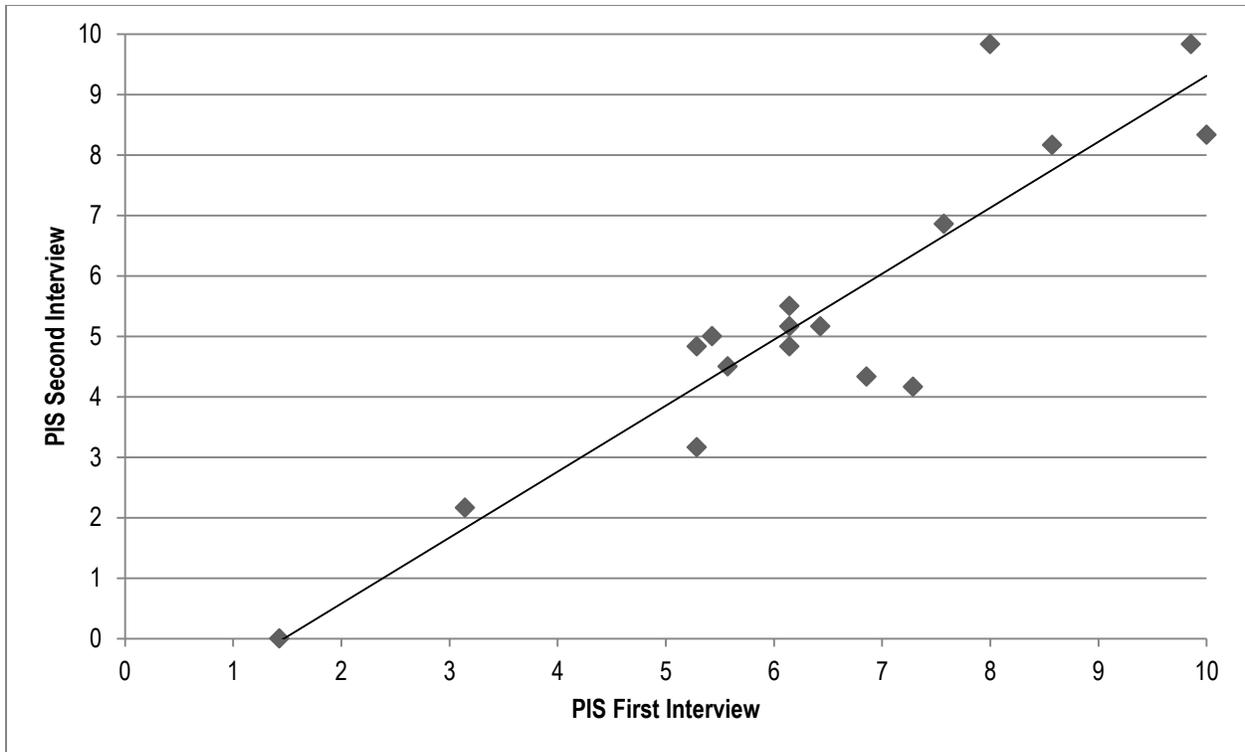


Figure 5-4: Scatterplot correlation of Pain Interference Scores [Pearson's  $r = 0.79$  ( $p < 0.05$ ) ( $n = 17$ )]

#### 5.4.3.3 CTQ-Xhosa

Thirty-one participants completed the CTQ initially, three failed to complete the CTQ at the second interview ( $n = 28$ ). Fourteen of the profiles were valid, 10 had some minimization or denial and seven had questionable profiles. There was strong agreement between the scores with Pearson's  $r = 0.97$  ( $p < 0.05$ ). For individual items in the instrument there was agreement for Emotional Abuse (Pearson's  $r = 0.92$ ;  $p < 0.05$ ); Sexual Abuse (Pearson's  $r = 0.98$ ;  $p < 0.05$ ), Physical Abuse (Pearson's  $r = 0.97$ ;  $p < 0.05$ ) and Emotional Neglect (Pearson's  $r = 0.7$ ;  $p < 0.05$ ).

#### 5.4.3.4 SE-6-Xhosa

Thirty participants completed the SE-6-Xhosa initially, one failed to complete the SE-6-Xhosa in the second interview ( $n = 29$ ). There was moderate agreement between the first and second interview in the scores for the SE-6-Xhosa (Pearson's  $r = 0.68$ ;  $n = 29$ ;  $p < 0.05$ ) (Figure 5-5).

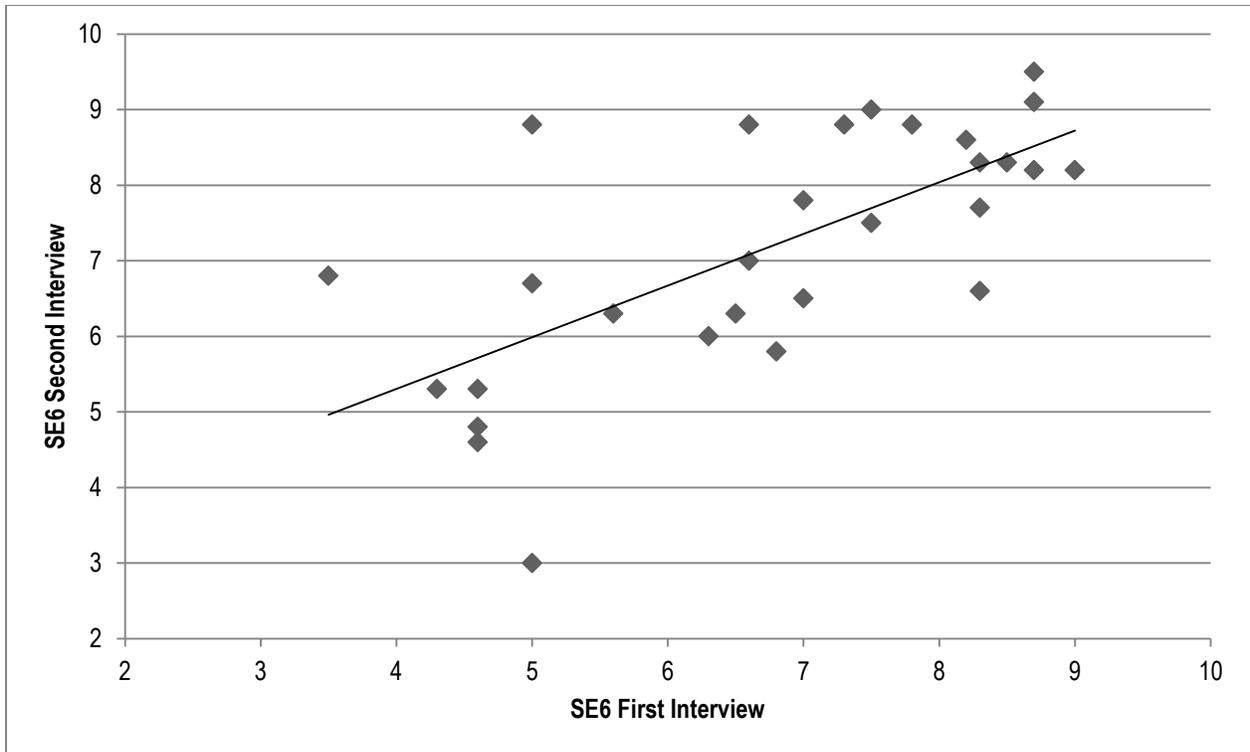


Figure 5-5: Scatterplot correlation for Self-efficacy scores [Pearson's  $r = 0.68$  ( $p < 0.05$ ) ( $n = 29$ )]

#### 5.4.3.5 EQ-5D-Xhosa

Twenty-nine participants completed the EQ-5D at both the first and second interview. Agreement between responses on the EQ-5D Xhosa health related quality of life instrument was explored using Pearson's correlation coefficient. There was excellent agreement between the first and second interview for the EQ VAS (Pearson's  $r = 0.95$ ;  $n = 29$ ;  $p < 0.05$ ) and good correlation for the EQ-5D index (Pearson's  $r = 0.7$ ;  $n = 29$ ;  $p < 0.05$ ).

#### 5.4.3.6 HTQ-Xhosa

Twenty-nine participants completed the Harvard Trauma Questionnaire at both interviews. There was excellent agreement between responses for the total HTQ scores (Pearson's  $r = 0.97$ ,  $n = 29$ ;  $p < 0.05$ ) and for the PTSD sub-score (Pearson's  $r = 0.96$ ;  $n = 29$ ;  $p < 0.05$ ).

#### 5.4.3.7 Beck depression inventory

Twenty-nine participants completed the BDI-Xhosa at both interviews. There was perfect agreement between responses at the first and second interviews with Pearson's  $r = 1.0$  ( $n = 29$ ;  $p < 0.05$ )

#### 5.4.4 Results summary

The validity and reliability of the instruments was calculated in a sample of amaXhosa women living with HIV/AIDS. The mean PSS scores of women responding to none, moderate and severe on the EQ-5D domain for pain/discomfort were significantly different. On confirmatory factor analysis, the BPI-Xhosa had a two factor structure (pain severity and pain interference). The BPI-Xhosa had good internal consistency for both the pain severity (0.77) and pain interference (0.83) subscales. The CTQ-Xhosa was found to have a five factor structure but factor loading for one factor was inconsistent. Removal of this factor (physical neglect) resulted in a four factor instrument with acceptable factor loading and internal consistency for each factor. The SE-6-Xhosa was found to have a single factor structure, convergent validity of the SE-6-Xhosa was determined with correlation of scores with the EQ VAS ( $r = 0.32$ ;  $p < 0.05$ ). Internal consistency of the SE-6-Xhosa was 0.74. As summarised in Table 5-13, all six instruments, BPI-Xhosa; CTQ-Xhosa; SE-6-Xhosa; EQ-5D; HTQ and BDI had acceptable agreement between responses on evaluation of test-retest responses.

Table 5-13: Summary of test-retest reliability testing

Test	Pearson's r	P value
<b>BPI-Xhosa (n = 17)</b>		
PSS	0.86	< 0.05
PIS	0.79	< 0.05
<b>CTQ-Xhosa (n = 31)</b>		
Emotional Abuse	0.82	< 0.05
Physical Abuse	0.98	< 0.05
Sexual Abuse	0.97	< 0.05
Emotional Neglect	0.70	< 0.05
<b>SE-6-Xhosa (n = 30)</b>	0.68	< 0.05
<b>EQ-5D-Xhosa (n = 29)</b>		
EQ VAS	0.95	< 0.05
EQ-5D index	0.7	< 0.05
<b>HTQ-Xhosa (n = 29)</b>		
Total score	0.97	< 0.05
PTSD	0.96	< 0.05
<b>BDI-Xhosa (n = 29)</b>	1.0	< 0.01

## 5.5 Discussion

In this chapter, the validity and reliability of the instruments used in the present study are presented. Full discussion of the sample and data gathered with the instruments is presented in Chapter 6. The validity and reliability of the instruments used in the present study were determined for a population of isiXhosa women living with HIV/AIDS who attended a community health centre for monitoring of their condition and live in a resource poor urban setting in Cape Town, South Africa. The women ranged in age from 19y to 40y with between three and 12 years of schooling. Use of the instruments in populations differing from that of the present study should be undertaken with caution<sup>152</sup>.

### 5.5.1 *Brief Pain Inventory - Xhosa*

The significant difference in mean PSS scores of women responding to none, moderate and severe on the EQ-5D domain for pain/discomfort indicate acceptable concurrent validity of the BPI-Xhosa with the EQ-5D-Xhosa. The EQ-5D has been widely used in various different amaXhosa sub-groups and has established validity and reliability. The excellent agreement between the instruments indicates good convergent validity.

Confirmatory factor analysis of the BPI-Xhosa confirmed a two-factor structure, pain severity and pain interference. Recent work by the designers of this instrument has revealed a three-factor structure in English speaking populations<sup>241</sup>. The three-factor structure is comprised of a pain severity factor and the pain interference factor dividing into pain activity interference and pain affective interference. A three-factor structure was identified in the similarly structured English South African version of the Wisconsin Brief Pain Inventory (WBPQ)<sup>12</sup>. However, evaluation of the WBPQ-isiZulu; WBPQ-Setswana and WBPQ-Xitsonga all revealed a similar two-factor structure as that found for the BPI-Xhosa<sup>12</sup>. It has been suggested that the three factor structure allows for greater clinical utility in the use of the instrument with different treatment components addressing each of the separate factors<sup>241</sup>.

The difference in factor structure may be a reflection of the translation process. Possibly the translated instrument was not sufficiently clear in these aspects to allow for differentiation. Alternatively the sample size might not have been large enough to allow for this breakdown in analysis. A difference in factor structure in different cultural groups may speculatively be a reflection of differences in cultural worldviews such as that recorded in the translation of the EQ-5D into Shona<sup>135</sup>.

It is possible that the two-factor structure in the BPI-Xhosa is a reflection of Xhosa culture; suggesting that there is less division in the interpretation of how pain impacts on individuals without division between activity interference and affective interference. However, this theory would need to be explored through qualitative research of the meaning of pain in this cultural group. In all four of the South African cultural groups in which this instrument (BPI) or the original version of the instrument (WBPAQ) has been validated (Xhosa, Zulu, Tsonga and Tswana) the two-factor structure was apparent. In all four of these groups it would be indicated to explore whether this is a consequence of methodological issues of translation or sample size or cultural interpretation.

Several different language versions of the BPI, including the isiZulu and Setswana versions, have had to exclude the item relating to “pain interference with sleep” as a result of poor factor loading<sup>12 146 247</sup>. Notably all the factors in the BPI-Xhosa loaded appropriately with none needing to be excluded. Further, the item “average pain” loaded clearly in the pain severity factor indicating that although the translation team was concerned about the interpretation of the item in isiXhosa (Section 4.3.3; Translation of the CTQ; p. 80), its meaning was maintained and interpreted as intended by the participants. Considering the translation team’s expression of concern regarding this item, loading of this item should be specifically re-evaluated if the instrument is used in a different population (e.g. rural or males).

The Cronbach alpha calculated for the BPI-Xhosa are similar to those calculated for BPI validations in other languages (Table 5-14) suggesting that measurement error in the isiXhosa version of the instrument is similar to that of other versions<sup>12 146 169 171 241 247</sup>. This facilitates the comparison of data between population groups and studies.

Table 5-14: Cronbach alpha for Pain Intensity and Pain Interference from the BPI or WBPQ in different languages

Language	Pain intensity ( $\alpha$ )	Pain interference ( $\alpha$ )
IsiXhosa	0.83	0.77
Chinese	0.86	0.91
English	0.87	0.91
English (South African) (WBPQ)	0.88	0.82
Filipino (Tagalog)	0.8	0.86
French	0.86	0.9
German	0.88	0.92
Greek	0.88	0.85
Hindi	0.89	0.91
IsiZulu (WBPQ)	0.80	0.73
Italian	0.78	0.78
Japanese	0.81	0.81
Korean	0.85	0.93
Malay	0.81	0.88
Norwegian	0.87	0.92
Setswana (WBPQ)	0.86	0.8
Spanish	0.87	0.89
Taiwanese	0.81	0.89
Vietnamese	0.85	0.93
Xitsonga (WBPQ)	0.84	0.94

### 5.5.2 *Childhood Trauma Questionnaire – Xhosa*

Confirmatory factor analysis revealed a poor fit between the current data and the proposed five-factor model of the original and Dutch versions of the instrument<sup>194 248</sup>. Factor analysis revealed a four-factor structure with the item for physical neglect not emerging. This is a similar finding to that reported in a group of female street-based sex workers in New York, USA<sup>198</sup> and in the validation of the Swedish version of the instrument<sup>195</sup>. It may be that the items comprising the physical neglect factor commonly occur in low-income communities and are a reflection of general hardship rather than abuse. In a population drawn from a resource poor setting such as in the present study, the frequency with which items of physical neglect are reported may not coincide with other items of neglect or abuse resulting in inconsistencies in the instrument. In addition to the items not loading on the physical neglect factor, there was inconsistency in items loading on the factor for emotional abuse with items loading onto more than one factor. Items loading onto multiple factors in this instrument has been reported previously and is suggested that it reflects the difficulty of creating items which distinguish between different forms of abuse<sup>198 249 250</sup>.

Acceptable internal reliability was found for the emotional neglect and emotional abuse factors with good reliability for the physical and sexual abuse factors. The internal reliability for the isiXhosa version of this instrument in this sample was better than that reported for the Swedish version of the instrument<sup>195</sup> suggesting that the meaning of the constructs were maintained from the original English version.

### 5.5.3 *Self-efficacy 6-item Scale - Xhosa*

The SE-6-Xhosa was found to have a single factor structure suggesting that like the original English<sup>216</sup> and translated German versions<sup>234</sup> of the instrument the items relate to a similar construct. Convergent validity was determined by comparing the SE-6-Xhosa to the EQ VAS using Spearman's rank correlation. Correlations of this type frequently occur between 0.2 and 0.6 with correlations greater than 0.4 regarded as good<sup>234</sup>. The correlation between these instruments was acceptable at 0.32 ( $p < 0.05$ ).

Reliability of the instrument was high with a Cronbach alpha of 0.72. The SE-6-Xhosa appears to have similar psychometric properties to the original English and the German versions of the instrument when used in isiXhosa women living with HIV/AIDs in a resource-poor community.

#### 5.5.4 *Intra-observer reliability*

There was good to excellent intra-observer reliability demonstrated for all the instruments indicating that there is minimal measurement error occurring when these instruments are administered by the specific research assistant working on this project.

## 5.6 Conclusion

The aim of this chapter was to validate and determine the internal consistency and test-retest reliability of the BPI-Xhosa, CTQ-Xhosa and the SE-6-Xhosa for use in a population of amaXhosa women living with HIV/AIDS resident in a resource poor community in Cape Town, South Africa. In the validation calculations, both the BPI-Xhosa and the SE-6-Xhosa were found to have similar psychometric properties to the original versions of the instruments. Although the CTQ-Xhosa did not retain the same psychometric properties as the original instrument, it has similar properties to the validated Swedish version. Therefore it appears to be valid to use all three instruments in this population which allows for comparison of data with other studies.

All three instruments were found to have acceptable reliability with alpha values of  $> 0.7$  on calculations of internal consistency. While the small sample used in the test-retest calculations was very small, limiting the results, these instruments appear sensitive for use in this sample to distinguish individuals from one another.

Finally, all six of the instruments (BPI-Xhosa, CTQ-Xhosa, SE-6-Xhosa, EQ-5D-Xhosa, BDI-Xhosa, HTQ-Xhosa) had good to excellent intra-observer reliability. Once again the small sample used in these calculations limits interpretation of the results but the good correlations are encouraging. From this data, it appears that the instruments are valid and reliable means to obtain information about pain, childhood trauma, levels of self-efficacy, health related quality of life, depression and likelihood of PTSD in amaXhosa women living with HIV/AIDS and living in an urban resource poor community. In the next chapter, a cross-sectional study utilising the above measurement instruments to explore the prevalence and characteristics of pain in amaXhosa women living with HIV/AIDS will be presented.

# Chapter 6: Pain in amaXhosa women living with HIV/AIDS

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## 6.1 Introduction

As discussed in the systematic review (Chapter 3), pain has been reported as the second or third most commonly reported symptom in PLWHA, whether or not they are receiving ART. The one week prevalence of pain was calculated as 60.81% [95%CI (58.55 – 63.025)] with several studies reporting on the inadequate management of pain in HIV/AIDS<sup>5 13 15 93 165</sup>. Highlighted in the systematic review was the high proportion of studies reporting on pain prevalence in ambulatory PLWHA from high income countries where HIV transmission is predominantly through homosexual contact and intravenous drug use (IDU). The paucity of studies exploring pain in ambulatory PLWHA in low and middle income countries was identified<sup>15</sup>. Other studies reporting on pain in PLWHA in South Africa have focused on inpatient groups<sup>11 93</sup>, common signs and symptoms in PLWHA<sup>42 64 251-257</sup>, quality of life in PLWHA<sup>64 83 85 252 257 258</sup> and the characteristics, contributing factors and management of painful peripheral neuropathy in PLWHA<sup>54 86 119</sup>. However, studies exploring the prevalence of pain in ambulatory AIDS patients in the many different cultural groups living in South Africa are limited and there is a need to fill this information gap.

Variables clearly identified to contribute to pain in PLWHA in different countries include being female, having low levels of education and ethnicity<sup>15 73</sup>. In South Africa, the HIV+ population is predominantly black, female (60%), and has not completed secondary level education<sup>15</sup> suggesting that this population is at increased risk of experiencing pain. Few of the studies reviewed in the systematic review (Chapter 3) focused on specific gender groups. Further, studies conducted in South Africa which considered ethnic and cultural groups explored prevalence of pain in Zulu, Venda and Tswana groups. Considering the influence of gender and ethnic group on pain prevalence, pain research which focusses on cultural and ethnic gender-specific groups is appropriate. The prevalence of pain, the functional impact of pain and the characteristics of pain in PLWHA from amaXhosa cultural groups is not known.

As discussed in Chapter 3, the factors which contribute to pain in PLWHA are varied ranging from the direct influence of the virus to the side effects of ART or the origin may be idiopathic<sup>116 259</sup>. The complexity of the pain experience presented in Section 1.2: Pain – a theoretical framework (p. 2), means that multiple factors may influence an individual's reporting of and response to pain and these may vary in different ethnic and cultural groups. Exploration of factors contributing to pain in different groups of PLWHA with pain is indicated.

Biological factors explored in previous studies include various disease parameters<sup>11 46 116 165</sup>. It is relevant therefore to explore disease parameters in relation to pain in ethnic and cultural groups where data are lacking. However, these are not the only factors which may contribute to pain and the psychosocial factors of self-efficacy (SE), HRQoL, depression and trauma also warrant investigation.

The role of SE in pain and effective management of chronic diseases was discussed in Chapter 4. People with pain and high levels of SE have lower reported levels of disability than people with the same amount of pain but lower levels of SE<sup>208</sup>. Similarly, women with fibromyalgia with higher levels of SE, have improved levels of physical activity and decreased symptom distress<sup>203</sup>. In a small group of homosexual males living with HIV/AIDS, increased levels of SE have been associated with decreased symptom severity and pain and fatigue<sup>127</sup>. However, the contribution of SE to pain in different South African ethnic and cultural groups is unknown.

As discussed in Chapter 3 and Chapter 4, HRQoL and pain in PLWHA appear inter-related<sup>74 83 85</sup>. In particular, one South African sample of PLWHA had a clear correlation between pain severity and reduced HRQoL<sup>86</sup>. Thus, HRQoL appears to be a critical factor in the prevalence of pain in PLWHA and is a relevant variable to be included in a study on pain in PLWHA.

Similarly, as the links between pain and depression have been identified in PLWHA with several of the studies reviewed in Chapter 3 reporting on this<sup>73 74 77</sup>, depression warrants inclusion in studies on pain in PLWHA. In addition to exploring the role of depression, the effects of previous trauma also merit study as a consequence of the possible sequelae. In Chapter 4, the links between post-traumatic stress disorder (PTSD) and pain in general were raised<sup>116 117 177</sup> as was the prevalence and impact of PTSD on pain in PLWHA<sup>116 189</sup>. In PLWHA, the trauma of being diagnosed with HIV and the repeated on-going stressors of declines in health, disclosing one's status, the onset of an opportunistic infection and the loss of a close family member may place PLWHA at increased risk of developing PTSD.

If these events are compounded by a previous history of childhood trauma then the risk of developing PTSD would increase. It is therefore relevant to explore the role of depression, PTSD and a history of childhood trauma on pain in PLWHA. Previous studies exploring pain in PLWHA from South African cultural groups have not explored the role of depression or PTSD. Considering the high prevalence of both depression and PTSD in South Africa<sup>189</sup>, these possible contributors to pain are worthy of exploration.

In the systematic review of the literature (Chapter 3), it became clear that women living with HIV/AIDS had a higher prevalence of pain than men living with HIV/AIDS. Pain perception and responses have been recognised to differ between men and women due to differences in physiological functioning<sup>102-104</sup>. However, differences in response may equally be affected by cultural gender differences<sup>103 105 106</sup>. Despite recognition of these gender differences, only two of the studies reviewed analysed data by gender or restricted their sample to one gender group<sup>80 89</sup>. Considering the differences in pain report and coping strategies used by men and women it is appropriate to restrict the sample group to one sex. Taking into account that the infection rate is highest among women in the Western Cape the current research will focus on this group<sup>260</sup>.

In addition, ethnic and cultural differences in pain prevalence were recorded in PLWHA<sup>97 107 108</sup> (Chapter 3). Considering both the influence of culture and ethnicity on gender roles, and on pain reporting and pain coping, it is pertinent to explore pain in different ethnic groups<sup>97 107 108</sup>. In view of the above factors, the research setting for the present study was a low-resource area in Cape Town, whose population is dominated by IsiXhosa speaking South Africans.

The community where this study was conducted has an estimated population of half a million people of whom 75% are under the age of 35<sup>261</sup>. One quarter of the population has a physical disability. Overall, the unemployment rate is estimated to be 60 – 70%. The majority of residents of this community live in shacks made from corrugated iron while 30% live in houses built on separate plots. Nearly 40% of residents do not have water at their homes and make use of communal taps and communal toilets. Up to 75% of residents have electricity with the remainder relying on paraffin stoves and lanterns for cooking, heat and light<sup>261</sup>.

The community health centre (CHC) where the study was conducted falls under the provincial department of health. The centre provides emergency services, has a midwife and obstetric unit, a pharmacy, an HIV ART clinic, physiotherapy, occupational therapy and a schools health service among others. The ART clinic at this community health centre is well established with over 4000 patients attending each month for free monitoring and treatment<sup>262</sup>. The study focused on amaXhosa women from this community, living with HIV/AIDS and receiving treatment at a community health centre.

## 6.2 Aims and objectives

The aim of this phase of the research was to establish the nature and extent of pain in amaXhosa women living with HIV/AIDS and determine the factors which may contribute to the presence and severity of pain in this group.

### 6.2.1 Objectives

There were several specific objectives. These included; in amaXhosa women living with HIV/AIDS to determine:

1. The prevalence, nature and duration of pain using the Brief Pain Inventory<sup>96</sup>.
2. The levels of self-efficacy using the Self-efficacy for Managing Chronic Disease 6-item Scale Xhosa<sup>210</sup>; the Health Related Quality of Life (HRQoL) using the EQ-5D<sup>145 263</sup> and symptoms of depression using the Beck Depression Inventory<sup>246</sup>.
3. The experience and impact of past traumas in amaXhosa women living with HIV/AIDS using the Childhood Trauma Questionnaire and the Harvard Trauma Scale<sup>191 194</sup>
4. What demographic and clinical factors, e.g. commencement of anti-retroviral therapy, past traumas (CTQ and HTS), symptoms of depression (BDI), and self-efficacy (SE-6) are determinants of pain in amaXhosa women living with HIV?

## 6.3 Method

### 6.3.1 Research design

A clinical analytical descriptive study was conducted using a cross-sectional design.

### 6.3.2 Subjects

A sample of convenience was utilized. AmaXhosa women aged 18 to 40 years, who had undergone HIV testing and were registered patients at a Community Health Centre HIV-clinic, were approached to take part in a study exploring quality of life in amaXhosa women living with HIV/AIDS. Inclusion criteria comprised being female, a first language IsiXhosa speaker, HIV positive (all clinical stages) and between 18 and 40 years old. As information was gathered by interview, literacy was not a requirement. Exclusion criteria included having moderate to severe intellectual disability or cognitive impairment restricting ability to participate in an interview.

Following identification of a CHC with an established ART clinic as a site for data collection, sample size was calculated based on the number of women registered with the clinic. Between 1 July 2009 and 31 July 2009, 2356 women were treated at the HIV clinic. Using the 60.81% prevalence of pain with a one week recall period as calculated in Chapter 2 as the mean expected prevalence of pain, sample size was calculated using Epi Info® (Version 7). For a population of 2356, using a 5% precision and a confidence interval of 95%, a sample of 317 was required. This implies that if the true prevalence is 60%, prevalence rates of between 55-65% will be accepted. Using a 90% confidence interval, a sample of 232 was required. Based on this data, a target of 250 participants was set for the study.

### 6.3.3 Instrumentation

The eight questionnaires presented in Chapter 4 and Chapter 5, were used to gather data (Appendix E). In addition a demographic questionnaire was developed. The instruments were:

1. Demographic questionnaire: demographic and personal characteristics including health status.
2. Brief Pain Inventory - Xhosa<sup>96</sup> to document prevalence of pain, pain severity, pain interference, pain sites and pain management.
3. The Xhosa version of the Self-efficacy for Managing Chronic Disease 6-item Scale to describe levels of self-efficacy of the individual<sup>210</sup>.
4. EQ-5D Xhosa to describe the health related quality of life<sup>149</sup>.
5. Beck Depression Inventory in Xhosa<sup>246</sup>
6. Childhood trauma questionnaire - Xhosa: history of childhood trauma <sup>178 194</sup>.
7. Harvard Trauma questionnaire in Xhosa: to explore likelihood of PTSD<sup>191</sup>.

A research assistant (RA) fluent in IsiXhosa and English with prior experience in data collection and a B.A. Honours (Medical Anthropology) was employed to conduct the data collection by interview. All interviews were conducted in IsiXhosa.

### 6.3.4 Procedure

Ethical approval was obtained from both the Faculty of Health Sciences Health Ethics Committee of the University of Cape Town (REC Ref: 420 2007) and the Province of the Western Cape Department of Health (Reference number: 19/18/RP12/2009) (Appendix B).

#### 6.3.4.1 Study procedure

Recruitment of participants took place during clinic hours between Mondays and Fridays from 8am to 2pm. These are the peak times of the clinic and recruitment was aimed at all those attending the clinic for scheduled appointments. Women attending the CHC for routine monitoring of their condition at the HIV clinic were approached by the RA while waiting for their files to be processed. The RA invited the women to take part in a study exploring quality of life in PLWHVA which would involve a one hour interview prior to their routine clinic consultation. Pain was expressly not mentioned. Patients who expressed an interest were provided with an information sheet (Appendix D). Patients who wished to participate in the study were then given the opportunity to have any questions answered by the RA prior to completing informed consent (Appendix D).

Participants were then interviewed by the research assistant in a private setting. Data was collected using a demographic questionnaire; the newly translated versions of the BPI-Xhosa, CTQ-Xhosa and the SE-6-Xhosa; and the previously translated and validated isiXhosa versions of the EQ-5D, BDI and HTQ. The RA accessed the patient's folder once all clinical documentation had been completed to obtain the most recent medical information for the demographic questionnaire.

Every participant was given the option of referral to appropriate services if this was required, e.g. to Social Services for a disability grant, to the Treatment Action Campaign or National Association of People With Aids for membership or to the nearest rehabilitation centre for further therapy. Patients presenting with symptoms indicative of psychiatric disorders were referred to the appropriate mental health services within the clinic.

#### 6.3.4.2 Pilot study

A pilot study was conducted with 30 participants. No procedural problems were identified. In the demographic data questionnaire, the item asking for number of dependents was incorrectly understood by the RA who recorded the number of family members living together ( $2 \pm 1.6$ ) rather than the number of people financially dependent on the participant. This issue was addressed with the RA adjusting the phrasing of the question. No other anomalies were identified and barring the item on dependents, the results from the pilot study were included in the final sample analysis.

### 6.3.5 *Ethical considerations*

The proposal was submitted to the Faculty of Health Sciences Research Ethics Committee. Following ethical approval, the project was submitted for review by the Provincial Health Department for ethical approval as the data collection would be conducted in a provincial community health centre. All participants were given an information sheet in their first language (Appendix D) and the opportunity to clarify any issues was provided prior to obtaining signed informed consent. Confidentiality of the data obtained was assured.

Confidentiality was maintained through the use of patient numbering. Those who chose not to participate in the study were reassured that this in no way affected their future treatment or access to care. If a participant's name was needed in order to refer them for further assessment or treatment, the participant's consent was obtained. All participant records were kept under lock and key. All reports on the study will maintain participant confidentiality.

There were several possible benefits for participants in taking part in the study. In completing a battery of questionnaires, the need for intervention was identified, and appropriate referral ensued. Participants identified to be at risk of mental health disorders following administration of the BDI and the HTQ were referred to the appropriate mental health services for management. Participants who were identified with disability were referred to the appropriate services. A further benefit of the study will be the dissemination of the results of the project to organisations meeting the needs of PLWHA, relevant authorities and the scientific community.

Harm may have arisen from the use of the CTQ and the HTQ. It is possible that participants may have become distressed recalling life events and the RA was encouraged to deal with these issues in a sensitive and professional manner and refer where appropriate. Conducting this series of interviews may have been distressing for the RA. In order to provide mental health support to the RA, monthly counselling appointments were arranged for the RA with an independent counsellor.

A final ethical consideration was the impact of the research on clinical service delivery. The procedure was designed to minimise the impact on service delivery in the clinic with participants being interviewed after clinic consultations to ensure that there was no impact on the normal running of the clinic. The RA was allocated a separate space to conduct interviews on the understanding that should clinical services require the space in acute situations it would take precedence.

### 6.3.6 Data analysis

Data were analysed using Statistica software (StatSoft, Inc. 2004. STATISTICA, Data Analysis Software System, Version 10. [www.statsoft.com](http://www.statsoft.com)). The STROBE guidelines were used to inform the design, analysis and presentation of data<sup>66</sup>. Descriptive statistics were calculated using summary statistics [means  $\pm$  SD and medians (range) for clarity] and frequency distributions where appropriate.

Pain, in particular the pain severity score (PSS) from the BDI-Xhosa was regarded as the primary outcome variable. The prevalence of pain is reported as the percentage with 95% confidence intervals. Data was examined for normality and subsequently comparisons were performed between those with pain (pain group) and those without pain (pain free group) for each of the secondary variables (SE, HRQoL, depression, childhood trauma and PTSD). Differences between the groups (pain group and pain free group) were calculated using t- tests for parametric interval data and chi-squared tests for nominal and ordinal data. The relationships between pain severity and pain interference and secondary variables were assessed using the Spearman's rank correlations. Spearman's  $r$  ( $r_s$ ) correlations were interpreted as weak (-0.3 - -0.1 and 0.1 – 0.3), moderate (-0.5 - -0.3 and 0.3 – 0.5) and strong (-1.0 - -0.5 and 0.5 – 1.0)<sup>264</sup>. All data are presented as the mean  $\pm$  standard deviation. Statistical significance was accepted as  $p < 0.05$ .

## 6.4 Results

Data were collected between 1 February 2010 and 3 December 2010. No data collection took place between 19 August, 2010 and 16 Sept, 2010 due to a strike in the public health sector which disrupted service delivery at the research site. Data collection in the time immediately following the strike action was reduced due to lack of capacity at the clinic. Data collection was not conducted during the summer holiday month of December 2010 due to markedly decreased attendance at the clinic during this time (this decrease in turnover occurs on a yearly basis as a consequence of summer vacations).

The sample will first be described followed by presentation of the descriptive data.

### 6.4.1 Socio-economic, demographic and clinical characteristics of the sample (N=224)

Two hundred and forty-eight women were recruited for the study, 245 met the inclusion criteria (3 of those recruited were over the age limit) (Figure 6-1). Data from 16 women was not included in the final analysis due to withdrawal during the interview or the research assistant being unable to trace the medical folder. The final sample consisted of 229 IsiXhosa women with HIV/AIDS aged between 18 and 40y.

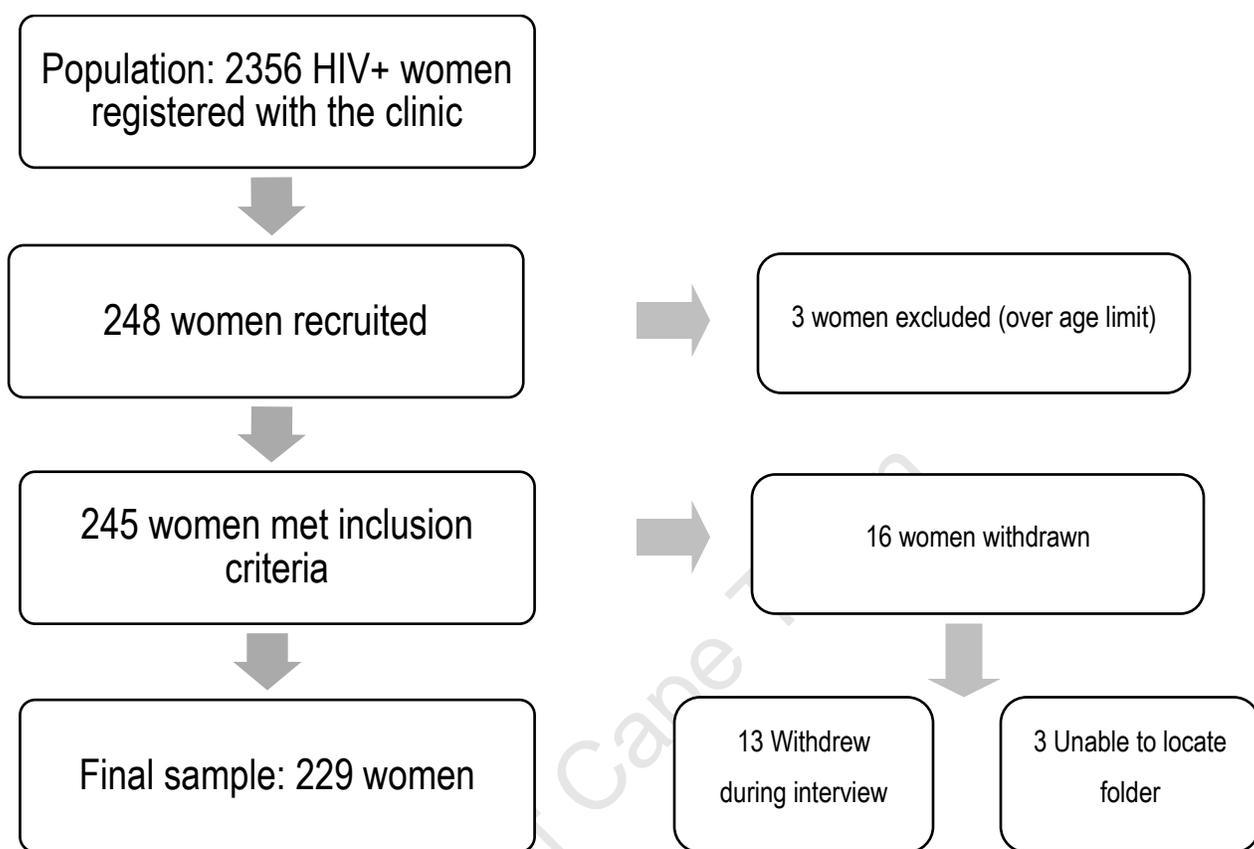


Figure 6-1: The sampling process

Descriptive characteristics of the participants are presented in Table 6-1 and Table 6-2. Results are presented for the sample ( $N = 229$ ), the participants reporting pain ( $n = 170$ ), and the participants reporting no pain ( $n = 59$ ). There were no significant differences between groups for age, the number of languages participants were able to speak or write, or marital status. Those with pain had significantly less time at school than those without pain ( $10.18 \pm 2$  years of schooling vs.  $10.93 \pm 1$  years of schooling;  $t = -2.98$ ;  $p < 0.01$ ). There were significant differences between groups in employment status ( $\chi^2 = 16.99$ ;  $p = 0.03$ ) and in number of years attending school.

Table 6-1: Age, number of languages and level of education of the sample ( $N = 229$ )

	Sample	Pain group	Pain Free Group	
	Mean $\pm$ SD (Range)	Mean $\pm$ SD (Range)	Mean $\pm$ SD (Range)	Significance Test
<b>Age</b>	N = 226	n = 170	n = 59	
Years	30.7 $\pm$ 5 (19 – 40)	30.9 $\pm$ 5 (19 – 40)	30.2 $\pm$ 5 (20 – 40)	t = 1.04; p = 0.3
<b>Languages</b>	N = 226	n = 170	n = 59	
Number of spoken languages	2.3 $\pm$ 0.6 (1 – 5)	2.3 $\pm$ 0.7 (1 – 5)	2.3 $\pm$ 0.6 (1 – 4)	t = -0.12; p = 0.9
Number of written languages	2.0 $\pm$ 0.6 (0 – 4)	2.0 $\pm$ 0.7 (0 – 4)	2.1 $\pm$ 0.5 (1 – 3)	t = -1.02; p = 0.31
<b>Educational Level</b>	N = 227	n = 169	n = 58	
Number of years in school	10.4 $\pm$ 2 (3 – 12)	10.2 $\pm$ 2 (3 – 12)	10.9 $\pm$ 1 (6 – 12)	t = -2.98; p < 0.01

Table 6-2: Employment and marital status of the sample (N = 229)

	Sample	Pain group	Pain Free Group	
	Number (%)	Number (%)	Number (%)	Significance Test
<b>Employment Status</b>	N = 228	n = 169	n = 59	$\chi^2 = 16.99$ ; p = 0.03
Unemployed	39 (17)	33 (19)	6 (10)	
Unemployed – seeking work	86 (38)	56 (33)	30 (51)	
Unemployed – receiving a disability grant	25 (11)	24 (14)	1 (2)	
In formal employment	38 (17)	26 (15)	12 (20)	
Homemaker/domestic worker	27 (12)	22 (13)	5 (8)	
Self-employed	3 (1)	1 (1)	2 (3)	
Working or has worked in health or social welfare	5 (2)	4 (2)	1 (2)	
Learner	5 (2)	3 (2)	2 (3)	
Missing	1 (0.5)	1 (2)	0 (0)	
<b>Marital Status</b>	N = 229	n = 170	n = 59	$\chi^2 = 2.41$ ; p = 0.79
Single	133 (58)	96 (56)	37 (63)	
Partner	47 (21)	38 (22)	9 (15)	
Married	36 (16)	26 (15)	10 (17)	
Separated	6 (3)	4 (2)	2 (3)	
Divorced	2 (1)	2 (1)	0 (0)	
Widowed	5 (2)	4 (2)	1 (2)	

As per the inclusion criteria, all participants in the study were HIV positive. HIV/AIDS history is presented in Table 6-3 and Table 6-4. Comparisons between groups revealed no differences between groups in the most recent CD4+ count, clinical stage at diagnosis, current clinical stage, number of years since diagnosis or number of months on treatment. Those without pain, had significantly lower CD4+ counts at diagnosis than those with pain ( $162.62 \pm 142$  cells/microL vs.  $233.52 \pm 185$  cells/microL,  $t = 1.99$ ;  $p = 0.05$ ). However, it should be noted that this data was only available for 132 of the participants. Analysis of current HIV management showed significant differences between the groups with more participants with pain on monitoring or first-line ARV management ( $\chi^2 = 12.12$ ;  $p = 0.02$ ).

Table 6-3: CD4+ count and length of time since diagnosis and initiating treatment (N = 226)

	Sample	Pain group	Pain Free Group	Significance Test
	Mean $\pm$ SD (Range)	Mean $\pm$ SD (Range)	Mean $\pm$ SD (Range)	
<b>CD4+ Count at diagnosis</b>	N = 132	n = 95	n = 56	
cells/microL	213.64 $\pm$ 185 (3 – 976)	233.52 $\pm$ 197 (3 – 976)	162.62 $\pm$ 142 (5 – 597)	t = 1.99; p = 0.05
<b>Most recent CD4+ count</b>	N = 221	n = 16	n = 56	
cells/microL	330.98 $\pm$ 212 (20 -1040)	328.36 $\pm$ 207 (20 – 1040)	338.68 $\pm$ 228 (20 – 1032)	t = -0.31; p = 0.75
<b>Time since diagnosis</b>	N = 147	n = 10	n = 40	
Years	4.2 $\pm$ 3 (0 – 19)	4.3 $\pm$ 3 (0 – 19)	3.8 $\pm$ 3 (0 – 14)	t = 1.01; p = 0.31
<b>Time since initiating treatment</b>	N = 226	n = 169	n = 57	
Months	23.8 $\pm$ 21 (0 – 96)	24.5 $\pm$ 22 (0 – 96)	21.9 $\pm$ 18 (0 – 62)	t = 0.57; p = 0.57

Table 6-4: Clinical stage and HIV management of the sample (N=229)

	Sample	Pain group	Pain Free Group	Significance Test
	Number (%)	Number (%)	Number (%)	
<b>Clinical Stage at Diagnosis</b>	N = 108	n = 75	n = 33	$\chi^2= 0.0001$ ; p = 0.99
HIV+ (Stage I and II)	59 (55)	41 (55)	18 (55)	
AIDS (Stage III and IV)	49 (45)	34 (45)	15 (45)	
<b>Current Clinical Stage</b>	N = 217	n = 162	n = 55	$\chi^2= 1.41$ ; p = 0.23
HIV+ (Stage I and II)	84 (39)	59 (36)	25 (45)	
AIDS (Stage III and IV)	133 (61)	103 (64)	30 (55)	
<b>Current HIV/AIDS Management</b>	N = 225	n = 168	n = 57	$\chi^2= 12.12$ ; p = 0.02
Monitoring	20 (9)	17 (10)	3 (5)	
First Line ARVs	180 (80)	136 (81)	44 (77)	
Second Line ARVs	15 (7)	12 (7)	3 (5)	
Pregnancy Prophylaxis	6 (3)	2 (1)	4 (7)	
Defaulted	4 (2)	1 (1)	3 (5)	

There was no difference between groups in current or past history of tobacco smoking or alcohol consumption (Table 6-5).

Table 6-5: Current and past smoking and alcohol consumption (N = 229)

	Sample	Pain group	Pain Free Group	
	Number (%)	Number (%)	Number (%)	Significance test
<b>Smoking</b>	N = 229	n = 170	n = 59	$\chi^2= 1.17; p = 0.56$
Currently smoking	198 (86)	145 (85)	53 (90)	
Previously smoked	24 (10)	20 (12)	4 (7)	
Never smoked	7 (3)	5 (3)	2 (3)	
<b>Alcohol consumption - Current</b>	N = 226	n = 168	n = 58	$\chi^2= 2.36; p = 0.88$
Not currently consuming alcohol	214 (94)	159 (94)	55 (93)	
Currently consuming alcohol	12 (6)	9 (6)	3 (7)	
<b>Alcohol consumption – Previous</b>	N = 220	n = 164	n = 56	$\chi^2= 12.25; p = 0.93$
Previously never consumed alcohol	114 (50)	80 (47)	34 (58)	
Previously consumed alcohol	106 (46)	84 (49)	22 (37)	

Anti-retroviral drug's known to be associated with the development of painful peripheral neuropathies [didanosine (ddl) and stavudine (d4T)] were being used by 23 (10%) of the participants. For the participants reporting pain, 18 (11%) were on either ddl or d4T; and 5 (9%) of the participants without pain were on either ddl or d4T. There was no difference between groups in the number of participants on these drugs. The full anti-retroviral drug data are presented in Appendix F (Table F-1; p. 303).

The most common opportunistic infections present at the time of the interview were tuberculosis and candidiasis (Table 6-6). Tuberculosis (pulmonary or extrapulmonary) was reported as present in 21 (9%) of the participants and candidiasis (oral or vaginal) in 9 (4%) of the participants. There was no difference between groups.

Table 6-6: Opportunistic Infections

	Sample (N = 229)	Pain group (n = 170)	Pain Free Group (n = 59)	Significance test
	Number (%)	Number (%)	Number (%)	
<b>Tuberculosis</b>	<b>21 (9)</b>	<b>19 (11)</b>	<b>2 (3)</b>	$\chi^2= 3.18; p = 0.07$
Extrapulmonary	10 (4)	10 (6)	0 (0)	
Pulmonary	11 (5)	9 (5)	2 (3)	
<b>Candidiasis</b>	<b>9 (4)</b>	<b>7 (4)</b>	<b>2 (3)</b>	$\chi^2= 0.06; p = 0.8$
Oral	6 (3)	5 (3)	1 (2)	
Vaginal	2 (1)	1 (1)	1 (2)	
Oral and vaginal	1 (0.5)	1 (1)	0 (0)	
<b>Other infections</b>	<b>10 (4)</b>	<b>10 (6)</b>	<b>0 (0)</b>	$\chi^2= 3.63; p = 0.06$
Genital Herpes	4 (2)	4 (2)	0 (0)	
Papular pruritic eruptions	2 (1)	2 (1)	0 (0)	
Meningitis	2 (1)	2 (1)	0 (0)	
Pneumocystis pneumonia	1 (0.5)	1 (1)	0 (0)	
Arthralgia	1 (0.5)	1 (1)	0 (0)	

The results for the sample, participants reporting pain and participants not reporting pain will now be presented for each of the standardised instruments used. Specifically results on pain from the BPI-Xhosa (participants with pain only); self-efficacy (SE-6-Xhosa); HRQoL (EQ-5D); depression (BDI); childhood trauma (CTQ-Xhosa) and adult trauma (HTQ) will be presented.

## 6.4.2 Pain

Prevalence of pain was 74.24% (95%CI 68 – 79%) when participants were asked the screening question from the Brief Pain Inventory – Xhosa: “Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain during the last week?”.

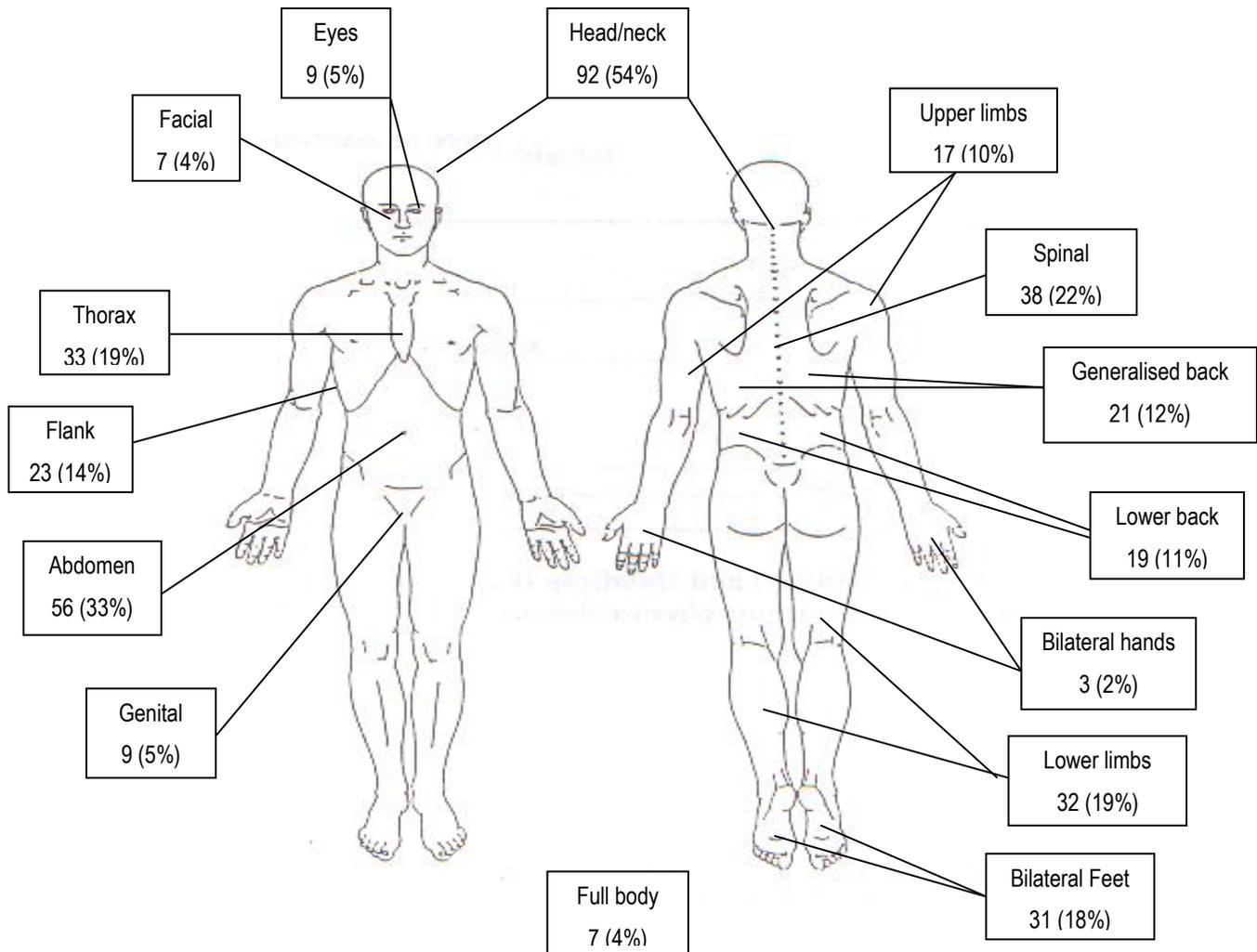
The full instrument was completed by the 170 participants who responded “Yes” to the above question. The Pain Severity Score (PSS) was calculated as the mean of the worst pain, least pain, average pain and pain now as described by the authors of the instrument<sup>96</sup>. Similarly the Pain Interference Score (PIS) was calculated as the mean of the seven items relating to pain interference. As presented in Table 6-7, the mean PSS was  $5.06 \pm 1.6$  (2 – 9) on a scale of 0 (no pain) to 10 (pain as bad as you can imagine). The mean PIS score was  $6.39 \pm 2$  (0 – 10) on a scale of 0 (no interference) to 10 (completely interferes).

Table 6-7: Pain Severity Scores and Pain Interference Scores from the BPI-Xhosa (n = 170)

	Mean $\pm$ SD (Range)
<b>Pain Severity Score</b>	<b>5.06 <math>\pm</math> 1.6 (2 – 9)</b>
Worst pain	7.52 $\pm$ 1.7 (3 – 10)
Least pain	4.65 $\pm$ 1.7 (1 – 10)
Average pain	3.93 $\pm$ 1.9 (0 – 10)
Pain now	4.14 $\pm$ 2.7 (0 – 10)
<b>Pain Interference Score</b>	<b>6.39 <math>\pm</math> 2 (0 – 10)</b>
Pain interference with activity	6.52 $\pm$ 2.6 (0 – 10)
Pain interference with mood	6.63 $\pm$ 2.8 (0 – 10)
Pain interference with ability to walk	6.18 $\pm$ 2.8 (0 – 10)
Pain interference with ability to do normal work	6.11 $\pm$ 2.7 (0 – 10)
Pain interference with relations with other people	5.89 $\pm$ 3 (0 – 10)
Pain interference with sleep	6.56 $\pm$ 2.8 (0 – 10)
Pain interference with enjoyment of life	7.07 $\pm$ 2.5 (1 – 10)

### 6.4.2.1 Sites of pain

On the body chart, participants indicated a mean of  $2.42 \pm 1.2$  (median 2; range 1 – 6) different anatomical sites of pain. The frequency of the most commonly reported different anatomical areas are presented in Figure 6-2. The most frequently reported region of pain was the head/neck region (92) followed by the abdomen (56).



*(Participants reported a mean of  $2.42 \pm 1.2$  different areas of pain at the time of interview)*

Figure 6-2: Frequency of most commonly reported painful anatomical areas

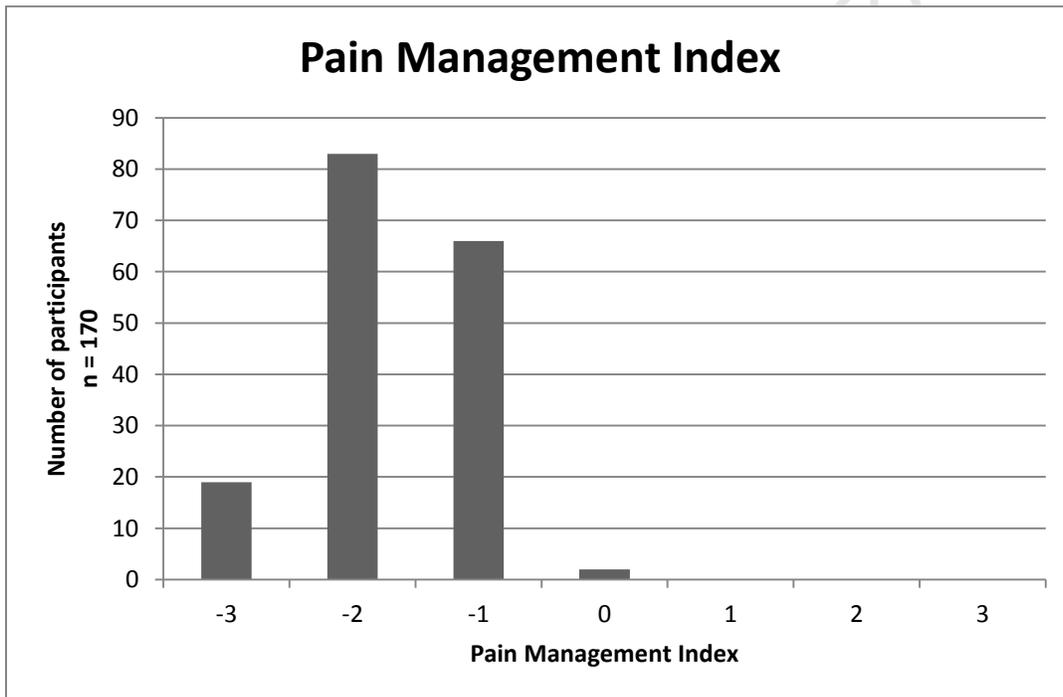
The areas of worst pain indicated on the body chart of the BPI-Xhosa are presented in Table 6-8. The most commonly reported region of worst pain was the head/neck region, with 47 of the 92 who reported pain in this region indicating that this was their area of worst pain.

Table 6-8: Anatomical area of worst pain as indicated on the body chart of the BPI-Xhosa (n = 170)

	Count	Percent (%)
Head/neck	47	28
Abdomen	32	19
Thorax	15	9
Spine	14	8
Lower back	10	6
Flank	8	5
Lower limbs	8	5
Eyes	6	4
Genital	4	2
Feet	4	2
Upper limb	3	2
Knee	3	2
Full body	2	1
Face	2	1
Feet and legs	1	1
Feet and hands	1	1
Wrist	1	1
Hip	1	1
Breasts	1	1
Feet and flank	1	1
Back	1	1
Axilla	1	1
Hand	1	1
Lower leg	1	1
Upper body and upper limbs	1	1
Missing	1	1

#### 6.4.2.2 Pain management index

The pain management index (PMI), a crude measure of the adequacy of pharmacological pain management, was calculated using the formula described by the authors<sup>96</sup>. To calculate the PMI, PSS are assigned a score of 0, 1, 2, or 3 with PSS of 1 – 4 = 1, PSS of 5 – 6 = 2 and PSS of 7 – 10 = 3. Using the World Health Organisation guidelines, analgesic medications are allocated scores according to strength with no pain medication = 0, nonopioids = 1, "weak" opioids = 2, and "strong" opioids = 3. The PMI score is calculated by subtracting the pain score from the analgesic score. A negative PMI score was considered an indicator of potentially inadequate pain management by the prescriber. The mean PMI score was  $-1.62 \pm 0.7$  (median -2, range -3 – 0). The distribution of PMI scores are presented in Figure 6-3. Two participants were receiving adequate pharmacological analgesic management for their pain according to WHO guidelines.



*(A score of  $\geq 0$  indicates adequate pharmacological management)*

Figure 6-3: Pain Management Index Scores (n = 170).

The most commonly used analgesic was paracetamol, used by 104 (61%) of those with pain. Non-steroidal anti-inflammatory drugs (NSAIDs) were used by 10 (6%) while a combination of paracetamol and NSAIDs were used by 23 (14%) of those with pain. As illustrated in Figure 6-4, 25 (15%) were using no analgesic therapy while the remainder were using a combination of paracetamol and adjuvant drugs (2 participants), paracetamol and a weak opiate (5 participants) and one participant was using paracetamol and a strong opiate. Pain relief obtained from medication is measured on the BPI on a 0% - 100% VAS. The mean pain relief obtained from taking analgesic medication (n = 162) was  $58.58 \pm 19\%$  (median 60%, range 0 – 100).

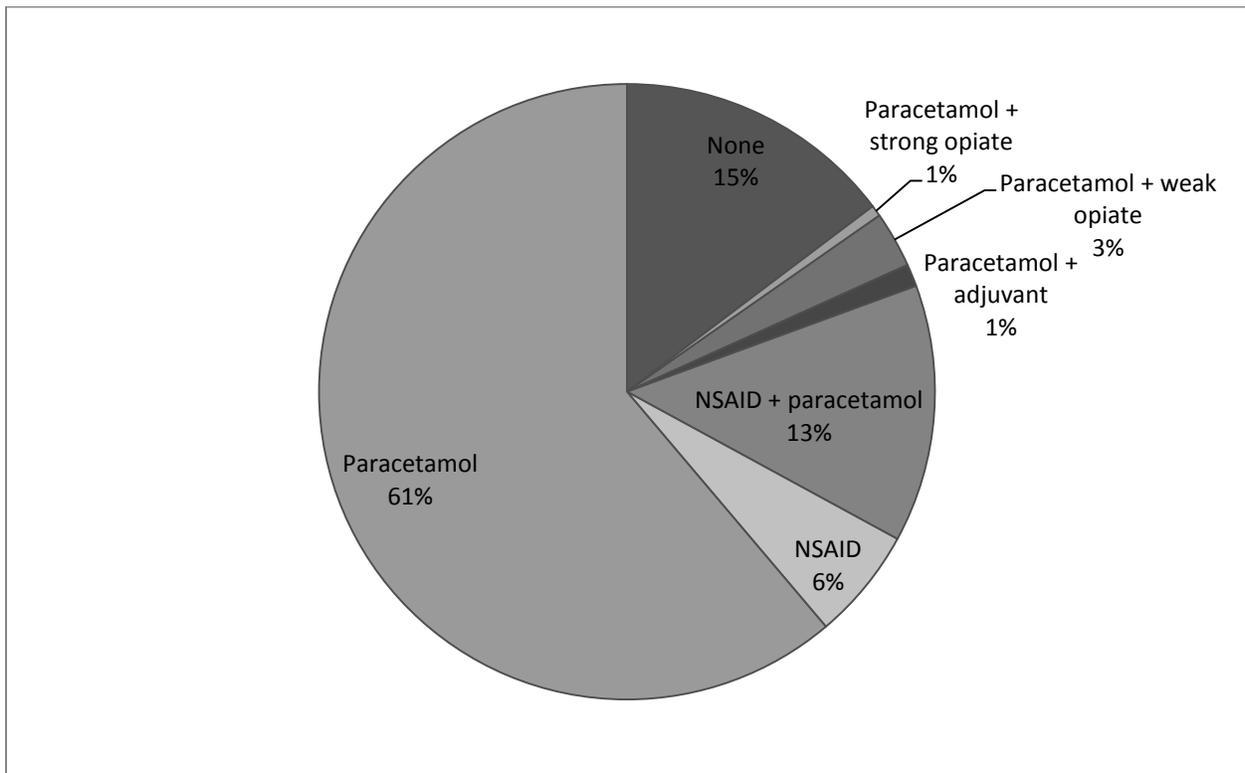


Figure 6-4: Pie chart of types of analgesic therapy reported by participants with pain (N = 170)

Relationships between PSS, PIS and PMI were explored. There was a moderate positive correlation between PSS and PIS indicating that as PSS increased (pain worsened) so PIS increased (interference from pain worsened) ( $r_s = 0.35$ ;  $p < 0.05$ ). There was a strong negative correlation between PSS and the PMI ( $r_s = -0.56$ ,  $p < 0.05$ ) indicating that as PSS increased (worsened) so adequate analgesic therapy as recorded on the PMI worsened. There was no correlation between PIS and the PMI.

### 6.4.3 Self-efficacy (N = 229)

The Self-efficacy for Managing Chronic Disease 6-Item Scale in Xhosa (SE-6-Xhosa) generates a single score for self-efficacy between one (not at all confident) and 10 (totally confident). The mean self-efficacy for the participants was  $6.6 \pm 1.6$  (median 7; range 3 – 10) (Table 6-9).

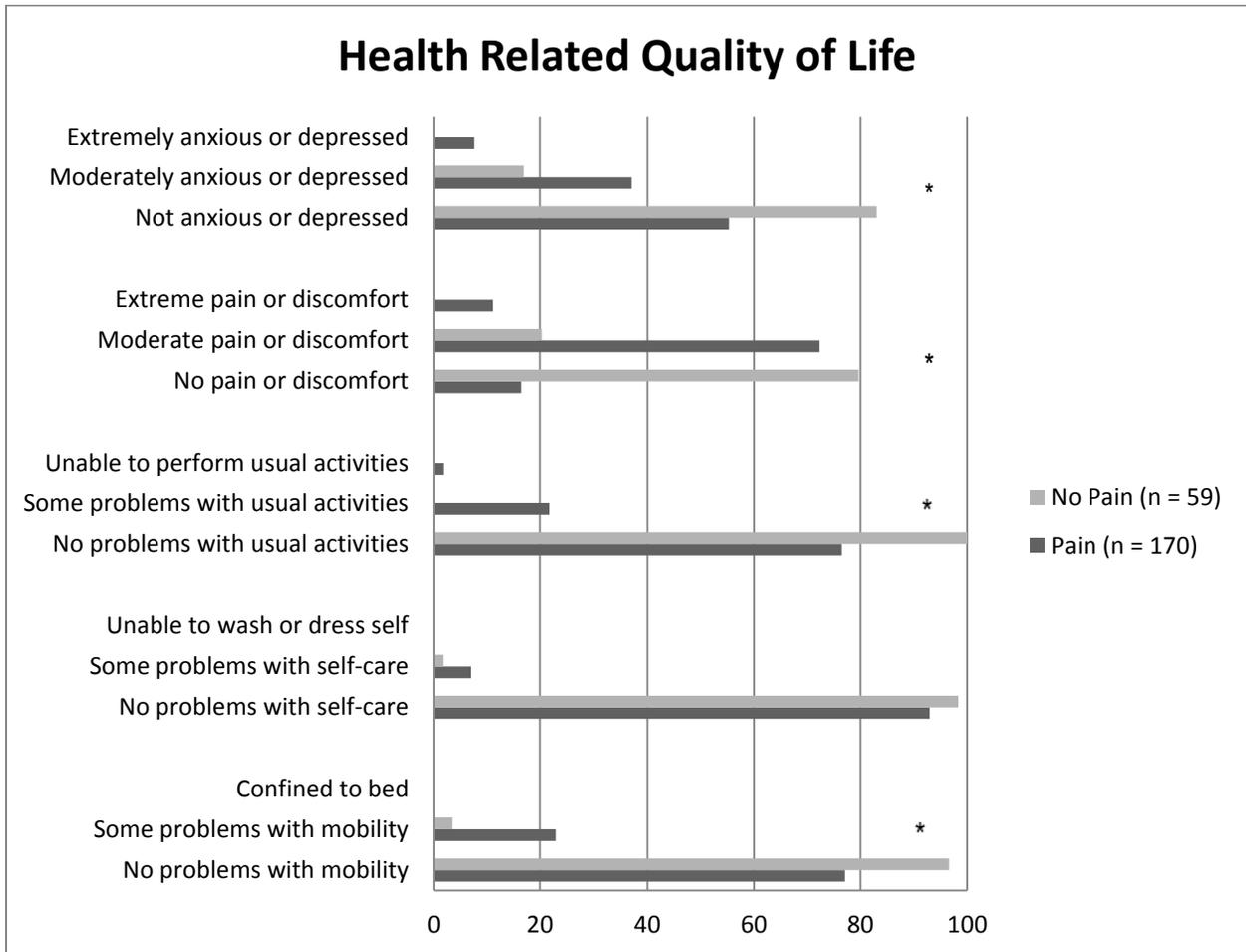
The total SE scores for those with pain were significantly lower than the scores for the pain free group ( $t = -2.4$ ;  $p = 0.02$ ) as were the scores for self-efficacy to manage pain ( $t = -2.6$ ;  $p = 0.01$ ).

Table 6-9: Self-efficacy scores for the sample, pain group and pain free group (N = 229)

	Sample (N = 229)	Pain group (n = 170)	Pain Free Group (n = 59)	Significance Test
	Mean $\pm$ SD	Mean $\pm$ SD	Mean $\pm$ SD	
<b>Self-efficacy score</b>	<b>6.59 <math>\pm</math> 1.6</b>	<b>6.45 <math>\pm</math> 1.6</b>	<b>7.00 <math>\pm</math> 1.5</b>	<b>t = -2.4; p = 0.02</b>
Fatigue	6.54 $\pm$ 2.4	6.42 $\pm$ 2.1	6.90 $\pm$ 2.3	t = -1.6; p = 0.11
Pain	5.76 $\pm$ 2.7	5.54 $\pm$ 2.4	6.41 $\pm$ 2.3	t = -2.6; p = 0.01
Emotional distress	6.54 $\pm$ 2.4	6.40 $\pm$ 2.7	6.95 $\pm$ 2.6	t = -1.5; p = 0.15
Other symptoms/health problems	6.42 $\pm$ 2.5	6.32 $\pm$ 2.4	6.71 $\pm$ 2.4	t = -1.1; p = 0.25
Tasks to manage health	7.05 $\pm$ 2.5	6.89 $\pm$ 2.5	7.52 $\pm$ 2.3	t = -1.7; p = 0.09
Things other than medicines to manage health	7.25 $\pm$ 2.4	7.16 $\pm$ 2.5	7.53 $\pm$ 2.3	t = -1.1; p = 0.27

#### 6.4.4 Health related quality of life (N = 229)

Health related quality of life was measured using the EQ-5D-Xhosa. The significant differences between the groups in the health related quality of life measures are clearly illustrated in Figure 6-5. Significant differences between groups were noted for the subcategories of mobility ( $\chi^2= 11.39$ ;  $p < 0.01$ ), usual activities ( $\chi^2= 16.82$ ;  $p < 0.01$ ), pain/discomfort ( $\chi^2= 80.09$ ;  $p < 0.01$ ) and anxiety/depression ( $\chi^2 = 15.47$ ;  $p < 0.01$ ). There was no difference between groups for the category of self-care ( $\chi^2= 2.35$ ;  $p = 0.13$ ).



\* Indicates significant difference between groups at  $p < 0.01$

Figure 6-5: Health Related Quality of Life as measured on the EQ-5D-Xhosa (N = 229)

The EQ-5D index of the sample was  $0.75 \pm 0.25$  (range -0.181 – 1.00) and the EQ VAS was  $73.6 \pm 18.6$  (range 10 - 100). As presented in Table 6-10, those with pain had significantly lower scores for the EQ-5D index than those without pain ( $t = -7.48$ ;  $p < 0.01$ ). Those with pain also had significantly lower scores on the EQ VAS ( $t = -5.98$ ;  $p < 0.001$ ).

Table 6-10: EQ-5D Index and EQ VAS HRQOL Scores (N = 229)

	<b>Sample (N = 229)</b>	<b>Pain group (n = 170)</b>	<b>Pain Free Group (n = 59)</b>	
	Mean ± SD (Range)	Mean ± SD (Range)	Mean ± SD (Range)	Significance Test
<b>EQ-5D Index (-0.594 -1.00)</b>	0.747 ± 0.245 (-0.181 – 1.00)	0.683 ± .0248 (-0.181 – 1.00)	0.932 ± 0.101 (0.656 – 1.00)	t = -7.48; p < 0.01
<b>State of health VAS (0 – 100)</b>	73.6 ± 18 (10 – 100)	69.5 ± 18 (10 – 100)	85.2 ± 14 (40 – 100)	t = -5.98; p < 0.01

#### 6.4.5 Depression (N = 228)

Symptom severity for depression was measured using the Beck Depression Inventory (BDI)<sup>246</sup>. The mean score for the sample was  $12.6 \pm 9$  (median 15, range 1 – 48). Figure 6-6 illustrates the differences in scores for those with pain (mean  $18.5 \pm 10$ ; median: 17; range 2 – 48) and for those without pain (mean  $12.6 \pm 9$ ; median 10; range 1 – 38). The group with pain had significantly higher BDI scores than the group without pain indicating more depressive symptoms ( $t = 3.9$ ;  $p < 0.01$ ).

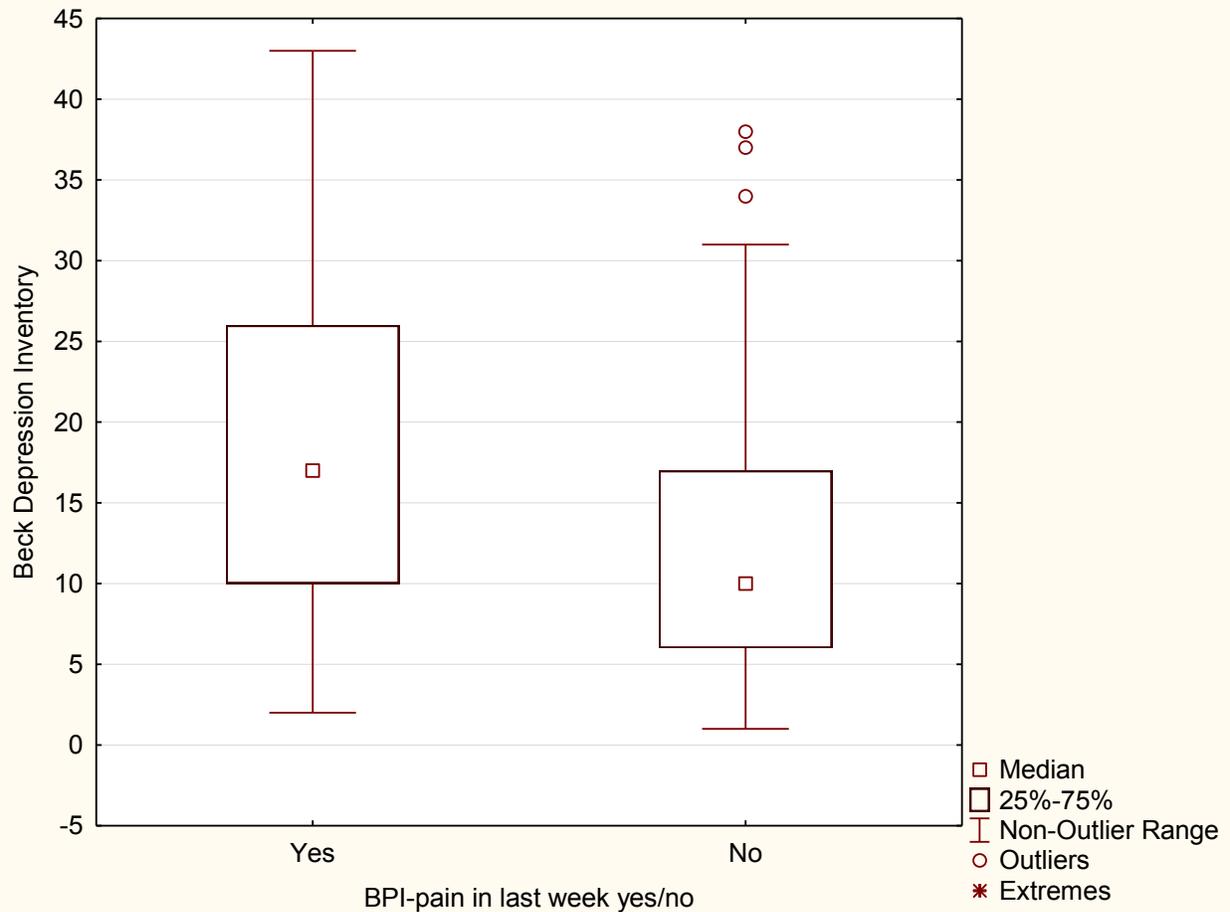


Figure 6-6: Beck Depression Inventory Scores

#### 6.4.6 Post-traumatic stress disorder (N = 214)

Two hundred and fourteen participants completed the Harvard Trauma Questionnaire to explore likelihood of PTSD<sup>191</sup>. The mean scores for the total sample, the cases and the controls were all less than two indicating that the group was not at increased risk of developing PTSD (Table 6-11).

There were significant differences between those with pain and those without pain. Those with pain had higher total scores indicating greater exposure to trauma ( $t = 2.22$ ;  $p = 0.03$ ) and higher scores on the PTSD subgroup indicating a higher likelihood of presenting with PTSD ( $t = 2.25$ ;  $p = 0.03$ ).

Table 6-11: Scores on the Harvard Trauma Questionnaire (N = 214)

	Sample (N = 214)	Pain group (n = 157)	Pain Free Group (n = 57)	
	Mean ± SD (range)	Mean ± SD (range)	Mean ± SD (range)	Significance Test
<b>Total Score</b>	1.69 ± 1.1 (0 – 3.83)	1.78 ± 1.1 (0 – 3.83)	1.41 ± 1.1 (0 – 3.47)	t = 2.22; p = 0.03
<b>PTSD Score</b>	1.74 ± 1.1 (0 – 3.75)	1.85 ± 1.1 (0 – 3.75)	1.46 ± 1.1 (0 – 3.50)	t = 2.25; p = 0.03

#### 6.4.7 Childhood trauma (N = 182)

All 229 of the participants completed the Childhood Trauma Questionnaire – Xhosa (CTQ-Xhosa). Of the profiles generated, 56 were classified as “questionable” according to the scoring guidelines of the instrument. Sub-analysis was conducted both with and without these profiles but there were no differences when the “questionable” participants were excluded. There was no difference for the total score of the CTQ-Xhosa between those with pain ( $41 \pm 9$ , range 29 – 84) and those without pain ( $39.8 \pm 10$ , range 26 – 73;  $t = 0.85$ ;  $p = 0.39$ ). In the sub-category analysis (Appendix F; Table F-3; p. 307), there was no difference between groups for the subcategories of emotional abuse ( $t = 0.19$ ;  $p = 0.06$ ); physical abuse ( $t = 0.23$ ;  $p = 0.32$ ); sexual abuse ( $t = -0.51$ ;  $p = 0.61$ ) or emotional neglect ( $t = 0.34$ ;  $p = 0.74$ ).

#### 6.4.8 Relationship between pain and other variables (n = 170)

Following identification of differences in the variables of number of years of schooling, self-efficacy, health related quality of life (EQ-5D index and EQ VAS), depression (BDI) and likelihood of post-traumatic stress disorder (HTQ) in participants reporting pain compared with those not reporting pain, relationships between each of these variables and pain severity (PSS), pain interference scores (PIS) and pain management index (PMI) scores were explored using a correlation matrix (Table 6-12).

Table 6-12: Correlation matrix for pain and biopsychosocial variables (n = 170)

	PSS	PIS	PMI	Years of school	SE-6- Xhosa	EQ-5D index	EQ VAS	BDI	PTSD
<b>Pain Severity Score (PSS)</b>	1.00								
<b>Pain Interference Score (PIS)</b>	0.35*	1.00							
<b>Pain Management Index (PMI)</b>	-0.56*	-0.14	1.00						
<b>Years of school</b>	-0.25*	-0.20*	0.14	1.00					
<b>SE-6-Xhosa</b>	-0.04	-0.13	-0.05	0.04	1.00				
<b>EQ-5D index</b>	-0.35*	-0.37*	0.09	0.25*	0.22*	1.00			
<b>EQ VAS</b>	-0.34*	-0.35*	0.14	0.29*	0.26*	0.64*	1.00		
<b>Depression (BDI)</b>	0.20*	0.44*	-0.04	-0.22*	-0.27*	-0.44*	-0.35*	1.00	
<b>PTSD</b>	0.10	0.19*	0.05	-0.12	0.11	-0.21*	-0.17*	0.36*	1.00

\*indicates significance at  $p < 0.05$

There was a weak negative relationship between PSS and number of years of schooling ( $r_s = -0.25$ ;  $p < 0.05$ ) and between PIS and schooling ( $r_s = -0.2$ ;  $p < 0.05$ ) indicating that as number of years of schooling increased, PSS and PIS reduced. There was a moderate negative relationship between the EQ-5D index and PSS ( $r_s = -0.35$ ;  $p < 0.05$ ) and PIS ( $r_s = -0.37$ ;  $p < 0.05$ ). There was also a moderate negative relationship between the PSS and the EQ VAS ( $r_s = -0.34$ ;  $p < 0.05$ ) and between the PIS and the EQ VAS ( $r_s = -0.35$ ;  $p < 0.05$ ). These indicate that as HRQoL improved, PSS and PIS reduced. Finally there was a weak positive relationship between the PSS and depression scores on the BDI ( $r_s = 0.2$ ;  $p < 0.05$ ) and a moderate positive relationship between the PIS score and depression on the BDI ( $r_s = 0.44$ ;  $p < 0.05$ ) indicating that as depression scores worsened so too did PSS and PIS.

#### 6.4.9 Summary of results

In this study, 229 amaXhosa women living with HIV/AIDS were interviewed. One hundred and seventy of the women reported experiencing pain in the last week, a prevalence rate of 74.24% (95%CI 68.2 – 79.47%). The mean PSS was  $5.06 \pm 1.57$  and the mean PIS was  $6.39 \pm 1.96$ . Only two women were receiving adequate pain management according to the PMI. Participants reported a mean of  $2.42 \pm 1.21$  (range of 1 -6) different anatomical sites of pain on the body chart. The most common anatomical region of pain was the head/neck area (reported by 92 participants) followed by abdominal pain (56 participants).

The group with pain had a greater number of unemployed participants ( $\chi^2 = 16.99$ ;  $p = 0.03$ ) and significantly fewer years of schooling ( $t = -2.98.5$ ;  $p < 0.01$ ). There were no differences between groups in the other demographic variables explored. With regard to disease parameters the pain group had a higher CD4+ count at diagnosis ( $t = 1.99$ ;  $p = 0.05$ ). A larger proportion of participants in the pain group were also only being monitored for their condition and were not receiving any ART at the time of the interview ( $\chi^2 = 12.12$ ;  $p = 0.02$ ).

The pain group had significantly lower scores on the SE-6-Xhosa, and for both the EQ-5D index and the EQ VAS. The participants with pain also had significantly worse scores for the categories of mobility, usual activities, pain/discomfort and anxiety/depression on the EQ-5D health related quality of life instrument. Regarding depression, those with pain had worse scores on the BDI indicating higher levels of depression. On the HTQ, the pain group scored significantly higher for PTSD than the pain free group. There were no differences between those with and without pain on the CTQ-Xhosa total score or in the sub-categories of emotional neglect, emotional abuse, physical abuse and sexual abuse. Low to moderate correlations were identified between PSS and number of years of schooling, the EQ-5D index, the EQ VAS and depression. In the next section, these results will be discussed in the context of the current literature.

## **6.5 Discussion**

The aim of this study was to explore the prevalence of pain in amaXhosa women living with HIV/AIDS and to describe the characteristics and factors contributing to pain. A pain prevalence rate of 74.24% (95%CI 68.2 – 79.47%) was recorded. This discussion will initially review the recruitment and size of the sample. The socio-economic, demographic and clinical characteristics of the participants will then be discussed prior to discussion on the prevalence of pain, the specific characteristics of pain including severity, pain interference, pain distribution and pain management. Finally factors which may contribute to pain will be discussed.

### **6.5.1 Sample**

Based on a population of 2356 women registered at the clinic for management of their HIV/AIDS condition, a target sample of 250 was set. Over a period of one year, 248 women were recruited to the study with 245 meeting the inclusion criteria. The final sample was reduced by the withdrawal of 13 women during the interview. These women withdrew due to time pressures in the clinic and the need to be seen by nurses or doctors or obtain medication from the pharmacy prior to closing and not due to the research study itself. The folders of three women recruited for the study could not be found at the clinic. Records at the clinic are held at three separate clinics, the HIV clinic, the general clinic and the maternity clinic.

When a patient moves from one clinic to another their folder is logged out and logged in to the new clinic. All three folders had been logged out of the HIV clinic but had not been logged in to either of the other clinics. The final sample consisted of 229 amaXhosa women living with HIV, an adequate number based on the sample size calculations.

### 6.5.2 *Socio-economic, demographic and clinical characteristics*

The socio-economic, demographic and clinical characteristics of the sample indicate that this group of women living in the community of Khayelitsha outside Cape Town had low income levels and low levels of education similar to the majority of female residents of the area<sup>265</sup>. The study focused on adult women on the basis that unlike in higher income countries, women bear the brunt of the HIV epidemic in South Africa<sup>36</sup>. Prevalence rates for HIV in 2011 for women aged 15 – 49 were 19.4% compared with prevalence estimates of 16% for adults of the same age range. The age distribution of the residents of Khayelitsha reveals a relatively young population with 45% of the population being between 15 and 34 years of age<sup>265</sup>. The average age of the participants was  $30.73 \pm 4.83y$ , representative of the large proportion of the population in this age bracket and the portion of the population with the highest prevalence rates for HIV/AIDS<sup>25</sup>.

IsiXhosa was the home language for all the participants in the study, reflective of the 96.8% of the population of the area who report the language as their home language<sup>265</sup>. The participants were able to speak and write an average of two different languages, with some participants able to communicate in up to five languages. While in some countries this might be regarded as a reflection of high levels of education, in South Africa this does not appear to be unusual and is a reflection of the multicultural nature of society in the urban areas of the country where English is the dominant medium of communication<sup>261</sup>. Exploration of level of education specifically reveals a relatively low level of education. Participants in the study had completed an average of 10 years of schooling with only 23% of the participants having completed 8 – 10 years compared with 46% of women in the area who have completed the same<sup>261</sup>.

With regard to employment, 65.5% of the participants were unemployed. This is a higher figure than that reported in the last census where 57% of the female population of Khayelitsha were recorded as unemployed<sup>265</sup>. However, this data needs to be interpreted with caution as the census data dates from 2001, and the latest census of 2011 may reflect different characteristics with employment figures changing as a consequence of economic depression. In the census figures of 2001, over 75% of households in the area were recorded as living below the household subsistence level (the level of income required to cover food, clothing, fuel, light, washing and rent and transport expenses).

Over half of the participants in the study reported that they were “single” (58%) with 20% having a partner and only 15% reporting being married. The large proportion of women reporting that they are single is similar to the figure from the last census of 55.8% of Black African women reporting they have never married. Similarly the distribution of participants reporting that they are married, divorced or widowed is consistent with the census figures<sup>261</sup>.

The majority of the participants were classified as having AIDS with 58% being classified as WHO Stage III or Stage IV. Further to this, 88% were receiving ART, a large proportion when compared with the national data from the Department of Health indicating that only 66% of people who need ART are receiving treatment<sup>1</sup>. This high figure is probably a reflection of the data collection site being a well-established ARV clinic and this might introduce a selection bias to the study.

The CD4+ counts indicate that at diagnosis the participants were relatively ill (CD4+  $213.64 \pm 185.32$  cells/microL) but that their health had improved with CD4+ counts increasing to  $330.98 \pm 211.89$  cells/microL\*\* at the time of interview. However the range of CD4+ counts reflect a more diverse state of health in the sample with the most recent counts ranging from 20 – 1040cells/microL. These figures suggest that some participants were gravely ill although only 38 participants (17%) were currently suffering from an opportunistic infection.

Over 80% of the participants reported that they were currently smoking, with only 10% reporting having previously smoked and only 3% indicating that they had never smoked. This is high even when compared with the figure of 40% for the female population of the Western Cape, the highest prevalence rate in the country<sup>266</sup>. However, over 90% reported currently not consuming alcohol consistent with the national mean of 85% of women not consuming alcohol<sup>267</sup>. The majority of those who were currently or had previously consumed alcohol had high levels of alcohol consumption consuming more than the recommended maximum of 14 units per week, a result consistent with the data indicating that binge drinking is associated with HIV infection.

In summary, the characteristics of the women participating in this study were similar to the majority of adult female residents of Khayelitsha. While it cannot be determined whether the participants are representative of women living with HIV/AIDS, this sample may represent the more severely affected as the women had already reported for treatment. The characteristics of pain in the participants will now be discussed with specific reference to factors contributing to pain.

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\*\* Normal CD4+ count is in the range of 500 to 1500 cells/microL

### 6.5.3 Pain

The prevalence of pain using a one week recall period in this group of women was 74.24% [95%CI (68.2 – 79.47%)]. This is markedly higher than the 60.81% [95%CI (58.55 – 63.025)] prevalence of pain using a one week recall period obtained in the systematic review of Chapter 3 but rather falls within the mid-point of the range (30 – 91%) reported by the papers included in the review<sup>6 14 88 90-92</sup>. This figure is also similar to the 72% prevalence of pain using a one month recall period reported in an ambulant HIV positive rural cohort of South Africans<sup>15</sup>.

It is notable that this is a higher prevalence of pain than previously reported in non-HIV+ groups living in the same area. A study exploring HRQoL of residents of Khayelitsha living with HIV/AIDS compared with a control group of residents, found a similar figure of 69.1% for the point prevalence of pain in the HIV group but only 33.3% prevalence of pain in the control group<sup>228</sup>. Although the details of the pain reported by Hughes and colleagues<sup>228</sup> are not available as the researchers only used the EQ-5D HRQoL instrument, there is one remarkable difference in the sample of the present study. The majority of the participants in the present study were receiving ART, while in the study by Hughes et al, participants were treatment naïve. A follow up study to that of Hughes and colleagues by Jelsma et al, explored changes in HRQoL one year after initiating ARV treatment<sup>85</sup>, found that HRQoL and prevalence of pain improved in correlation to time on ART. Point prevalence of pain reduced from 70% at baseline to 40% at six months and only 26.5% one year after initiation of treatment. These results are incongruent with the present study. Being on treatment did not seem to play a role in the presence of pain in the present study participants with no differences in length of time since initiating ART between those with pain and those not experiencing pain. Possible reasons for this incongruence relate to differences in the sample. Compared to the present study, the sample in the previous studies by Hughes and colleagues and Jelsma and colleagues were of mixed gender and all participants were classified as being in Stage III or Stage IV and were receiving ART.

There are several previously identified factors which may explain why the pain prevalence rate for a one week recall period was higher than the 60.3% obtained from the pooled data in the systematic review (Chapter 3). The higher prevalence of pain in the present study compared with that in the systematic review may be a consequence of variations in measurement instruments. In the systematic review, various translated versions of the WBPQ and the BPI were used which may have introduced some variation in the data. However, several psychosocial factors may also contribute to this difference. The first lies with the gender of the sample. Previous studies have identified being female as a risk factor for pain in HIV/AIDS<sup>14 15</sup>. While the inclusion of women only in the present study was purposive in an attempt to identify factors which may contribute to pain that are particular to this group who form the majority of HIV/AIDS patients in South Africa, the higher prevalence of pain may simply be a reflection of this and an indication of how much being female increases risk for pain.

The second factor relates to socio-economic status which has also been identified as a risk factor for pain<sup>14</sup>. More than half of the participants were unemployed (66%) and the significantly higher rates of unemployment in the participants reporting pain (Table 6-2, p.131) suggest that this may have contributed to pain in this sample. In addition, previous studies have identified low levels of education as increasing risk for pain<sup>82 268</sup>. The majority of the sample in the present study had not completed all 12 years of schooling in South Africa, with those reporting pain having significantly lower levels of education than those without pain (Table 6-1, p. 130).

Previous studies have repeatedly found few links between disease parameters and pain in PLWHA<sup>43</sup>. This was also the case for the participants in this study with no differences in clinical stage between those with pain and without pain and no differences in most recent CD4+ count and length of time since initiating treatment (Table 6-3, p.132). There was a difference between groups in HIV/AIDS management with a larger proportion of those with pain only being monitored for their condition. Given that there was no difference in CD4+ counts between the groups, it does not seem logical to suggest that an increase in pain is a consequence of a lack of treatment as the disease indicators do not correspond.

The specific characteristics of the pain experienced by the sample will now be presented.

#### 6.5.3.1 Pain severity and pain interference

The mean PSS ( $5.06 \pm 1.57$ ) indicates that participants had moderate pain<sup>24</sup>. Moderate pain is recognised to interfere with cognition and function suggesting that the pain experienced by this group was severe enough to affect their quality of life and require treatment<sup>43 132</sup>. The mean score for the category of worst pain was  $7.52 \pm 1.73$ , indicating severe pain and greater levels of suffering. These scores are similar to those reported in the urban and rural South African cohorts recently studied by Mphahlele and colleagues<sup>15</sup> and in older studies conducted in higher income countries<sup>6 14 92</sup>. However, the PSS in this study is lower than that reported on in other South African studies, probably as a consequence of selection bias. The studies with more severe PSS, report on IP populations of PLWHA compared with the ambulatory outpatient populations in the present study<sup>11 93</sup>. It might be expected that poorer health states and opportunistic infections would contribute to more severe pain when pain is present.

Similarly the mean PIS ( $6.39 \pm 1.96$ ) indicates moderate interference with life roles as a result of pain. Pain interfered most with enjoyment of life, a similar result to that reported in a cohort in the USA<sup>14</sup>. However, the PIS was markedly higher than that reported in both a rural and an urban South African cohort where the PISs were only 1.3 and 0.5 respectively<sup>15</sup>. The difference in PIS may be a reflection of a different measurement instrument as, although the study conducted in the USA used the BPI, the South African study used the WBPQ with a different presentation and different Likert scale scoring of the pain interference items.

There was only a moderate correlation between PSS and PIS; (Table 6-12, p. 145) suggesting that pain severity is not the only factor contributing to how patients cope with the symptom. This relationship between PSS and PIS reinforces the findings of Mphahlele and colleagues who reported on the stoicism of their participants who, despite moderate to severe levels of pain, reported low to moderate levels of PIS<sup>15</sup>. This was particularly notable in their participants in a rural area, with the authors theorising that perhaps living conditions were such that participants could not afford to allow pain to interfere with their function as this would impact on basic survival. The lack of association between pain severity and disability is recognised in the literature relating to musculoskeletal pain and cancer pain with disability relating more to psychosocial factors such as catastrophic thinking and beliefs about the pain than with the severity of the pain<sup>269</sup>. Thus in disadvantaged population, it may be proposed that pain interference is influenced by a multitude of variables such as cultural beliefs, education and socio-economic level and is not simply a direct consequence of pain severity.

In addition to providing information on pain severity (PSS) and pain interference (PIS), the BPI also provides information on sites of pain and pain management.

#### 6.5.3.2 Sites of pain

The participants reported a mean of  $2.42 \pm 1.21$  different sites of pain on the body chart. This number of areas is remarkably similar to that reported in the studies reviewed in Section 3.4.5: Characteristics of Pain (p. 44). It appears that across the literature describing pain in PLWHA that when pain is present, it occurs at at-least two distinct sites at any one time.

The most commonly reported sites of pain were the head/neck region followed by the abdomen, spine and feet. This is a similar pattern of pain reported in the South African metropolitan cohort studied by Mphahlele and colleagues<sup>15</sup>. The widespread anatomical sites of pain are noteworthy as a review of the literature suggests that pharmacological management of pain in PLWHA focuses on painful peripheral neuropathy which presents with bilateral foot pain followed by bilateral hand pain when severe<sup>181 270-276</sup>. However, the data from this study and others on pain in PLWHA indicate that further research into effective management approaches is needed in order to address the widespread pain experienced.

### 6.5.3.3 Pain management

While it must be acknowledged that the PMI is a crude measure of the adequacy of pharmacological pain management, it is notable that only two participants in this study were receiving adequate analgesic therapy. This is not a unique finding and it is disturbing considering that the under-treatment of pain in PLWHA has been raised in the literature for nearly 20 years<sup>14 44</sup>. This lack of adequate analgesic management has been reported in other studies in South Africa in both inpatient<sup>93</sup> and outpatient groups<sup>15</sup>.

Despite the poor results on the PMI, 85% of participants were receiving some form of analgesic therapy. A high proportion when compared with previous studies of South African PLWHA where less than 20% were reported to be using analgesics<sup>15 86 93 228</sup>. It is acknowledged that the Western Cape region, where the present study was conducted, has had greater success in the rollout of ARVs<sup>39</sup>. The greater proportion using analgesics (even if inadequate analgesics) may be a reflection of access to treatment in this province compared with the provinces where the previous studies were conducted.

The majority of participants were using paracetamol to manage their pain (Figure 6-4, p.139). Compared with previous studies, According to the PMI, paracetamol is classified as a mild analgesic and is indicated for use with mild pain (a pain score of 1 - 3 on a 0 – 10 VAS). Considering that the mean PSS was a five, indicating moderate pain and that the mean worst pain score was in the severe category, the participants in this study should have been receiving weak opioids and strong opioids to manage their pain. A recent review of pain in HIV has emphasised the need for integrated pain assessment and management in PLWHA reiterating that management of the disease itself does not reduce pain but that the symptom deserves individualised treatment<sup>43</sup>.

Despite the apparent under management of pain according to the PMI, the participants reported  $58.58 \pm 18.87\%$  pain relief when they used the analgesics they were provided. This response may formerly have been dismissed as a placebo effect indicative of a psychosomatic source of pain. However, recognition that placebo analgesia is largely a downward mediated endogenous opioid mechanism which can be learnt through social conditioning prevents this assumption<sup>277</sup>. PLWHA with pain may be reducing their pain through placebo analgesia as a consequence of expectation that the medication provided will be effective, a response known to occur in both laboratory and clinical settings<sup>278</sup>.

The levels of self-efficacy, HRQoL, childhood trauma, depression and PTSD in the participants will now be discussed prior to discussion on the predictors of pain in this sample.

#### 6.5.4 *Self-efficacy*

The self-efficacy scores for managing chronic disease in the participants were relatively high ( $6.59 \pm 1.59$ ). However, the developers of the SE-6 report that persons living with chronic diseases often report high levels of SE with mean scores of seven out of ten commonly occurring<sup>279</sup>. The scores in this study may be normal for a group of people living with a chronic disease, however, this instrument has not previously been used in isiXhosa and although carefully translated (Chapter 4) and found to be reliable (Chapter 5) its validity has not been explored.

Participants with pain had significantly lower scores for SE than those without pain (Table 6-9; p.140); this was the case for both the total score and the SE for managing pain. As discussed in Section 4.2.4 (p.73), SE has been linked with pain in several different conditions with low levels of SE being associated with higher pain severity and greater levels of pain related disability<sup>132 199 200 208</sup>. From this result, the inter-relationships between pain and SE were explored.

#### 6.5.5 *Health related quality of life*

The HRQoL of the participants is presented using the EQ VAS, the EQ-5D index and the categorical factors of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The participants reported a mean state of health on the VAS of  $73.56 \pm 18.58$ . This is a score similar to that reported in other studies conducted in this community<sup>85 228</sup>. The scores for those with pain were significantly lower than for those without pain (70 vs. 85; Table 6-10; p.142). As previously discussed, a reduced HRQoL has previously been identified in studies conducted in South Africa and elsewhere in PLWHA and having pain<sup>74 86</sup>. Therefore this finding of reduced HRQoL is not unexpected.

In the categorical descriptors for quality of life, the domains with the greatest number of participants indicating problems were pain/discomfort and anxiety/depression (Figure 6-5, p.141). Problems were also identified in the domains of mobility, self-care and usual activities. Again these findings are similar to those previously reported in PLWHA living in this community<sup>228</sup>. Clearly those with pain would have greater problems in the domain for pain/discomfort but it is notable that those with pain also had greater problems in the domains of mobility, usual activities and anxiety/depression.

In a cross-sectional study such as this one is not possible to determine whether HRQoL is influenced by the presence of pain or whether a low HRQoL increases risk of pain. It appears intuitive to suggest that the presence of pain would reduce HRQoL. A similar argument could be proposed for the identified problems in the domains of mobility, usual activities and anxiety/depression. Notably, a lack of physical activity is recognised to contribute to chronic pain, as are anxiety and depression<sup>132</sup>. Therefore it is worth exploring further whether these factors independently contribute to pain in PLWHA and were thus included in the predictive model.

### 6.5.6 *Depression*

As suggested by the responses in the domain of anxiety/depression on the EQ-5D, the mean score for the BDI was  $17 \pm 10.39$ . A score of  $> 13$  can be regarded as indicative of depressive symptoms; the participants in this study could be suggested to be depressed<sup>246</sup>. However, despite the common use of this instrument in South African populations, only literature supporting the reliability of this instrument in South Africa was found<sup>280</sup> and the validity of this cut-off in South African population groups could not be established. It is notable that when scores for depression were explored by group, the mean score for those with pain remained above the 13 point score ( $18.54 \pm 10.42$ ) while those without pain were below this theoretical cut-off score ( $12.59 \pm 9.04$ ). As mentioned in the previous section on HRQoL, the links between pain and depression are well recognised in the pain literature and have previously been identified in studies reviewed in Chapter 2 exploring pain in PLWHA<sup>73 74 77</sup>. Once again, causality cannot be determined using a cross-sectional design; however the close links between pain and depression are apparent and the role of depression as a contributor to pain (with pain recognised as a symptom of depression<sup>118</sup>) was explored further.

### 6.5.7 *Post-traumatic stress disorder*

Scores of greater than two on the HTQ are regarded as indicative of PTSD. The mean score for participants in this study was below two suggesting that they were unlikely to suffer from this condition. However, it has been noted that the Xhosa version of the instrument may not be as sensitive as the original and therefore making absolute interpretations based on the data is not recommended<sup>189</sup>. Participants with pain did have significantly higher scores on the instrument than those without pain suggesting a higher likelihood of PTSD in this group (Table 6-11; p. 144).

Living with HIV has been proposed to increase likelihood of PTSD<sup>116 189</sup>. Similarly PTSD is known to contribute to chronic pain states<sup>269</sup> and to pain in PLWHA<sup>116</sup>. The increased scores for PTSD in those with pain are not unexpected and the role of PTSD as a contributor to pain was explored further.

### 6.5.8 *Childhood trauma*

Comparison of those with pain to those without pain revealed no differences between the groups in overall score on the CTQ-Xhosa suggesting that a history of childhood trauma may not play a role in pain in amaXhosa women living with HIV/AIDS. In the sub-category analysis there were no differences in the domains of emotional abuse, emotional neglect, physical abuse and sexual abuse.

The relationships between pain and the variables in which there were differences between those with pain and those without pain will now be discussed further.

### 6.5.9 *Relationship between pain and other variables*

Level of education as represented by number of years of schooling was negatively correlated to both pain severity and pain interference scores. This association between level of education and pain in PLWHA has previously been identified by several authors<sup>43 165</sup>. Low levels of education are relevant when the literature emphasising the need to educate persons living with chronic diseases in order to minimise symptoms, improve adherence and HRQoL is considered<sup>281</sup>. To maximise efficacy, educational interventions need to be developed for the appropriate educational level.

There were no relationships between SE and either PSS or PIS. Thus while it has been proposed that raising levels of SE improve pain and other symptoms in chronic diseases<sup>281</sup>, it appears that SE may not directly affect pain in HIV/AIDS but rather changes in SE may occur secondary to change in other variables.

There was a negative relationship between both the EQ-5D index and the EQ VAS and both PSS and PIS indicating that as pain severity or pain interference worsened, so HRQoL decreased. As was discussed earlier, in a cross-sectional study the causality of this relationship cannot be established. There were weak and moderate positive relationships between scores for depression on the BDI and both the PSS and PIS indicating that as pain severity and pain interference worsened, so too did depression. There was a stronger correlation between the BDI and PIS suggesting that depression affects ability to cope with pain more than the severity of the symptom.

Considered within a biopsychosocial framework for pain, relationships between PSS and PIS and the various psychosocial variables is not surprising. Using the ICF as a framework, it is possible to map the numerous variables which may contribute to pain in PLWHA as illustrated in Figure 6-7. In this sample of amaXhosa women living with HIV/AIDS, lower levels of education were associated with increased pain. Previous studies have identified a similar pattern with low educational levels being associated with lower levels of SE, higher mental health disorders and symptoms, including pain<sup>282</sup>. Based on the biopsychosocial model, lower levels of education may not only increase the chances of developing symptoms, but also contribute to symptom severity as a consequence of lower SE. Identifying the interaction between these psychosocial variables and pain, allows for the development of non-pharmacological treatment strategies which may have a positive outcome on pain. While it is acknowledged that correlations provide limited insight into the relationships between variables, it may be suggested that addressing educational gaps in this group of PLWHA may impact on pain. Peer-led and expert-led education interventions have been used in HIV/AIDS<sup>126</sup> and other chronic diseases such as arthritis and diabetes<sup>281</sup> with resultant reductions in symptom severity. In addition, physiotherapy interventions aimed at improving strength and physical fitness in PLWHA have been found to improve function and increase levels of SE<sup>122</sup>. Such interventions would specifically address problems with mobility and activity which may subsequently result in a reduction in pain.

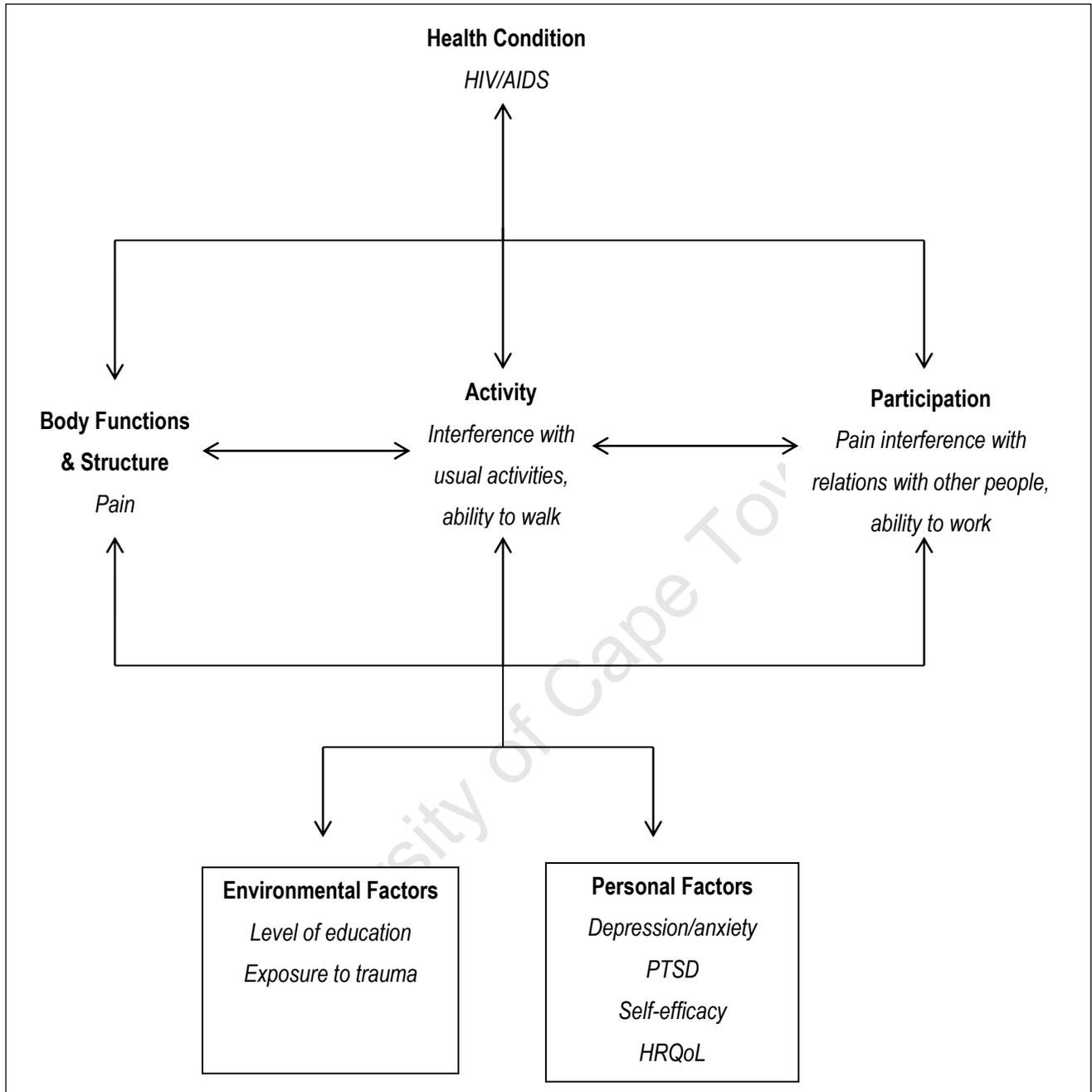


Figure 6-7: Diagrammatic representation of the ICF with pain and other variables identified to interact with pain in PLWHA

### 6.5.10 Limitations of the study

The guidelines for strengthening reporting of observational studies in epidemiology (STROBE) were used as a benchmark for evaluating study limitations<sup>66</sup>. The guideline criteria are presented in Table 6-13 with indication of how these were addressed in the study.

Table 6-13: Evaluation of study in relation to STROBE guidelines

Item	Item No	Recommendation	Section where this was addressed
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract  (b) Provide in the abstract an informative and balanced summary of what was done and what was found	Abstract
<b>Introduction</b>			
Background	2	Explain the scientific background and rationale for the investigation being reported	Section 6.1
Objectives	3	State specific objectives, including any prespecified hypotheses	Section 6.2 with specific objectives in Section 6.2.1
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	Section 6.3.1
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Study setting described in Section 6.3.2  Periods of recruitment and data collection are described in Section 5.4
Participants	6	Give the eligibility criteria, and the sources and methods of selection of participants	Section 6.3.2
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Section 6.3.4 Section 6.3.6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Section 6.3.3 Section 6.3.4
Bias	9	Describe any efforts to address potential sources of bias	Section 6.3.4
Study size	10	Explain how the study size was arrived at	Section 6.3.2
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Section 6.3.4

Item	Item No	Recommendation	Section where this was addressed
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Section 6.3.6
		(b) Describe any methods used to examine subgroups and interactions	N/A
		(c) Explain how missing data were addressed	N/A
		(d) If applicable, describe analytical methods taking account of sampling strategy	Section 6.3.6
<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Section 6.4 Section 6.4.1
		(b) Give reasons for non-participation at each stage	
		(c) Consider use of a flow diagram	Figure 6-1
Descriptive data	14*	(a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders	Section 6.4.1
		(b) Indicate number of participants with missing data for each variable of interest	Numbers reported for each instrument as N for the total sample and n for sub-groups
Outcome data	15*	Report numbers of outcome events or summary measures	Numbers reported for each instrument as N for the total sample and n for sub-groups
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Method described in Section 6.3.6. Confidence intervals provided,
		(b) Report category boundaries when continuous variables were categorized	Category boundaries provided
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses	N/A
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	Section 6.4.9

Item	Item No	Recommendation	Section where this was addressed
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Section 6.5.10
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Section 6.5
Generalizability	21	Discuss the generalizability (external validity) of the study results	Section 6.5.10

The main limitation of this study relates to sampling bias which limits generalizability of the data. The study's specific aim was to explore pain in AmaXhosa women living with HIV/AIDs. The sample studied was drawn from a single site in an urban resource poor setting, introducing a selection bias which may have influenced results. The data should thus be interpreted with consideration of this bias.

## 6.6 Conclusion

The aims of this study were to establish the prevalence of pain in amaXhosa women living with HIV/AIDS and to explore the characteristics and contributing factors to pain in this sample. The prevalence of pain using a one week recall period in this group of amaXhosa women was 74.24% (95%CI 68.2 – 79.47%); a rate markedly higher than the 60.3% (95% CI 57.71 – 62.84) calculated in the systematic review of Chapter 3. The PSS and PIS of this sample were in the moderate range, similar to those reported in previous studies. In addition, the women had marked under-treatment of pain according to the pain management index. A result similar to those reported elsewhere.

As has been reported elsewhere there were no significant differences in any disease parameters in those with pain. Perhaps not surprisingly the women with pain had worse scores than those without pain in a wide range of demographic and psychosocial variables. Those with pain were worse off in terms of levels of education, SE, HRQoL (in particular relating to usual activities and mobility), depression and PTSD. This is not unexpected if pain is considered within a biopsychosocial framework which emphasizes the complex nature of the pain experience encompassing these factors and numerous others not measured in this study.

### *6.6.1 Clinical implications and recommendations*

This study reinforces the high prevalence, severity and under-management of pain previously reported in PLWHA. It also highlights that pain may be more common in amaXhosa women living with HIV/AIDS than other groups of PLWHA. These data emphasise the need for pain to be regularly assessed in PLWHA. The South African clinical guidelines for the management of HIV/AIDS can be strengthened on the basis of this data by including pain assessment and management guidelines. Routinely assessing for the presence of pain in PLWHA has the potential to improve pain management and minimise the impact of pain on function.

### *6.6.2 Research implications and recommendations*

The correlation analysis identified variables which may be impacted on through non-pharmacological interventions. Studies exploring the effect of exercise and other functionally focused rehabilitation interventions such as patient education could inform management approaches, and, if effective, provide an alternative treatment approach for pain in PLWHA. Research on the development of such interventions and randomised controlled trials on their effectiveness in specific patient groups is indicated.

In conclusion, pain is a common problem for amaXhosa women living in an urban setting with HIV/AIDS. The pain is of moderate severity, interfering with function and quality of life. Further, there is marked under-treatment of this pain. This study highlights the need to prioritise pain assessment and management in amaXhosa women living with HIV/AIDS and highlights the possible role for non-pharmacological management approaches. In the following chapter, the development of an intervention programme for pain in amaXhosa women living with HIV/AIDS will be presented followed by the results of a trial of its effectiveness.



# Chapter 7: The effects of a six-week peer-led exercise and education intervention on pain in amaXhosa women living with HIV/AIDS

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## 7.1 Introduction

Pain is a problem for PLWHA around the world. Further, as presented in the previous chapter, 74% of amaXhosa women attending a community health centre in the resource poor suburb of Khayelitsha in the Western Cape of South Africa for management of their HIV/AIDS reported experiencing pain in the previous week. Pain in these women was not associated with disease factors such as stage of illness or CD4+ count but was associated with problems with functioning (performing usual activities and mobility) and decreased educational level (number of years of schooling). This is consistent with the biopsychosocial model of pain presented in Section 1.2 Pain – a theoretical framework (p.2) and suggests that to effectively manage pain in PLWHA addressing biological or disease factors alone will not be effective and that a holistic approach is needed.

Chronic disease management models have adopted the holistic biopsychosocial approach with the aim of decreasing the impact of symptoms such as pain (morbidity) and mortality. These models focus on multidisciplinary management where the empowered patient is recognised as an active member of the team<sup>283-285</sup>. Chronic diseases in which this approach has been successfully adopted include diabetes, arthritis, asthma and chronic pain disorders<sup>286-290</sup>. The model encompasses the use of pharmacological approaches with non-pharmacological approaches such as exercise, education and psychological treatment. A key component of this model is a structured health education intervention aimed at enabling patients with chronic disorders through increasing knowledge and self-efficacy to achieve behaviour changes advantageous to health.

In this chapter, the development of an intervention for amaXhosa women living with HIV/AIDS will be presented. The aim being to develop an intervention which could be peer-led and which incorporated the evidence based strategies of education and exercise to increase self-efficacy. This section will be followed by reporting of a study to test the effects of this intervention on pain in a group of amaXhosa women living with HIV/AIDS.

## 7.2 Development of an intervention for amaXhosa women living with HIV/AIDS

As previously mentioned, intervention programmes aimed at empowering patients living with a range of chronic diseases have been found to be effective in decreasing symptom severity (including pain), increasing adherence, increasing quality of life and decreasing health system usage<sup>286-290</sup>. Interventions using health education based on a social behaviour model which focuses on raising levels of self-efficacy have frequently been used in patients living with chronic diseases<sup>283</sup>. Self-efficacy is an individual's belief in their ability to succeed in different situations<sup>291</sup>. People with high levels of self-efficacy believe themselves able to cope with their illness both in managing its treatment and in coping with symptoms. A change in self-efficacy beliefs is associated with an increase in self-management ability<sup>242</sup>. Interventions focussing on changing self-efficacy beliefs have been reported to improve disease outcome by up to 30%, decrease number of symptoms, improve symptom management and reduce cost of medical management in patients with arthritis and other chronic conditions<sup>209 284 292 293</sup>. Although levels of SE were not found to be associated with pain in the present study, it has been previously reported that increased levels of self-efficacy were associated with decreased symptom severity in a small group of homosexual males<sup>127</sup>. Good management of medication and fewer symptoms result in decreased reliance on medical support systems and improved quality of life<sup>294</sup>.

While health education is a cornerstone to improving knowledge and self-efficacy beliefs and promoting health, it is recognised that didactic education alone does not lead to a change in behaviour. Didactic health education programmes have been found to have limited effectiveness in managing function in people with chronic diseases<sup>2 295</sup>. In order for changes in knowledge and beliefs to translate into behaviour changes which will have a positive impact on function and quality of life, cognitive behavioural approaches; primarily through goal-setting, need to be adopted<sup>2</sup>. Therefore effective patient education programmes aim to change knowledge, self-efficacy beliefs and health behaviours in order to improve symptom severity and management, quality of life, adherence and reliance on medical services<sup>296</sup>.

A similar approach of patient empowerment through education and change in behaviour is adopted in chronic pain management programmes<sup>297</sup>. Chronic pain management programmes have developed education programmes combined with exercise based on cognitive behavioural principles to facilitate changes in behaviour<sup>298</sup>. These programmes link education on the pathology of chronic pain and health promotion with progressive goal oriented exercise programmes and have been found to have an effect on pain and function up to six months post intervention<sup>299</sup>. The integration of exercise into these programmes has been found to have multiple beneficial effects including enhancing changes in self-efficacy beliefs, decreasing fear avoidance behaviours, increasing activity levels and decreasing disability. In combined education and exercise interventions based on cognitive behavioural principles, patients increase knowledge and learn to apply that knowledge through practical goal setting, thus increasing self-efficacy through personal experience (setting goals and achieving them), vicarious experience (group work), verbal persuasion (education) and physiological states as they derive benefit from increased levels of fitness and strength and learn to cope with physical symptoms. The principles applied in chronic disease and chronic pain have also been used in programmes developed for PLWHA<sup>127 300</sup>.

### *7.2.1 Chronic disease management programmes for PLWHA*

Several different intervention programmes aimed at empowering PLWHA and improving disease and symptom management, function, quality of life and adherence have been developed and studied. These programmes have used varied approaches ranging from didactic group education<sup>301</sup>; cognitive behavioural therapy (CBT) (individual<sup>302</sup> and group approach<sup>303</sup>), a combination of peer and expert-led education<sup>2 282</sup> and expert led exercise<sup>122 304</sup>. These interventions have been reported to have moderate effects on a variety of outcomes. However, none of these interventions have been designed to address pain as the primary objective.

#### 7.2.1.1 Didactic education

Wellness programmes for persons living with HIV/AIDS use a combination of strategies to educate and support PLWHA including didactic education such as pamphlets and educational talks<sup>301</sup>. While these strategies do appear to have a positive effect on knowledge if they are appropriately adapted for the target culture, their effect on health behaviours appear to be limited. The limitations of didactic health education in various formats (pamphlets, lectures, film and audio) which seem to entrench the passive role of the patient as a receiver of care have been widely reported<sup>305</sup>.

### 7.2.1.2 Cognitive Behavioural Therapy

In a New York study exploring the effects and feasibility of individual CBT in PLWHA and suffering from peripheral neuropathy both CBT and supportive psychotherapy, delivered weekly over six weeks, decreased pain and its effects<sup>302</sup>. The study compared the effects of CBT in four women and 24 men compared with the effects of supportive psychotherapy in nine women and 24 men. On the BPI, the participants were suffering from moderate pain with moderate interference with function. The majority, 66%, were receiving ART.

Although the results demonstrated an improvement in pain, there was a nearly 50% drop-out rate for participants in both arms of the study (CBT and supportive psychotherapy) leading the authors to question the acceptability and utility of these interventions. Similarly, Trafton and colleagues<sup>303</sup> reported high drop-out rates in a group CBT intervention aimed at managing pain in PLWHA. However, analysis by intention to treat in this study found that despite poor group attendance, the intervention had beneficial effects on pain severity and interference with functioning. It would appear that these interventional approaches, both individualised and group interventions, were effective in reducing pain although the poor attendance in both studies is a concern.

### 7.2.1.3 Peer- and expert-led education

Gifford and colleagues<sup>127</sup> reported on a pilot randomised trial of a six week health education programme in 71 HIV positive men living in the San Francisco area of the USA. Participants reported decreased symptom severity and increased levels of self-efficacy following participation in the group. This education programme was well received by the participants who reported at a later date that they had benefited from it<sup>2</sup>. The study has limited generalizability, as the participants were a small sample of homosexual men. However, positive responses were similar to those found for other chronic disease programmes and suggest that this approach may be acceptable and effective for a broad segment of PLWHA.

A more recent study used the same intervention in a group of women living with HIV/AIDS in the USA<sup>282</sup>. In this study, no differences were reported between the experimental (who received the intervention and the workbook) and control (who received the workbook only) groups over time. The author suggests that the lack of effect was due to the intervention having been designed for homosexual males resulting in the information not being targeted to the needs of women living with HIV/AIDS. In addition, the original intervention was designed and tested in the 1990's, a time when the approach to HIV management was in transition compared with the current chronic disease management model used in HIV/AIDS. However, the participants in the intervention were very positive when interviewed and felt that should their specific needs be addressed the programme would be enhanced. Notably, while both this study and that by Gifford and colleagues included education on exercise and other practical techniques for the management of chronic diseases, they did not include any practical exercise or goal setting components.

#### 7.2.1.4 Exercise interventions

Several studies have identified the safety and benefits of exercise in PLWHA. PLWHA frequently report using exercise to manage their symptoms<sup>4 13</sup>. An early study on the effects of a supervised training intervention found that HIV+ men attained significant benefits including improvements in strength and cardiovascular function but no changes in disease parameters when they trained for a period of 12 weeks<sup>304</sup>. Further, a six-month trial of a cardiorespiratory training programme in Rwandans living with HIV/AIDS and receiving ART was found to be effective in improving quality of life, decreasing central adiposity and improving metabolic indices<sup>306 307</sup>. This work conducted in a low income country illustrates the utility of exercise as a health intervention as well as demonstrating the efficacy of the treatment. In a more recent randomised controlled trial of a six-month physiotherapist supervised aerobic and resistance exercise programme for PLWHA in Australia, increased levels of strength and fitness in addition to increases in self-efficacy and health related quality of life were recorded in the experimental group<sup>122</sup>.

Muscle wasting associated with HIV/AIDS has multiple effects including decreased function which progressive resistance training may effectively minimise. Strength training may also minimise the effects of lipodystrophy, one of the side effects of ART<sup>306</sup>. A Cochrane review of the literature reports that aerobic exercise is a safe method to increase cardiovascular fitness in people living with HIV/AIDS and leads to a significant reduction in depressive symptoms<sup>125</sup>. A further Cochrane review exploring the efficacy and safety of strength training for PLWHA reports that this intervention could play an important role in HIV/AIDS with improvements in body weight and body composition being reported<sup>124</sup>. Exercise is safe for use in PLWHA, is recommended in education programmes for PLWHA, is commonly used by PLWHA to control symptoms<sup>4 13</sup> and is therefore an effective approach which can be integrated into programmes to facilitate behaviour change in this group.

No literature was found reporting on the efficacy of an intervention programme using a combination of exercise and education strategies in PLWHA aimed at addressing pain in PLWHA. Therefore, an intervention programme was developed with the aim of using exercise and education to facilitate increases in knowledge and self-efficacy beliefs and decreases in symptom severity (specifically pain) and functional impact. The components of the intervention and motivation for their selection will be presented; followed by presentation of a study on the effect of the intervention programme on pain in amaXhosa women living with HIV/AIDS.

## 7.2.2 *Intervention programme content*

A six-week peer-led exercise and education intervention programme was developed for the present study based on self-efficacy theory<sup>291</sup> using the principles of social learning and cognitive behavioural therapy such as problem solving and goal setting to achieve behaviour change and build confidence<sup>127 202 210</sup>. The “Positive Living” programme which was developed (Appendix G), integrated the principles of chronic pain management programmes and other chronic disease management programmes which use self-efficacy theory and the principles of self-management<sup>127 202 208 283 295 308-312</sup>.

The programme was specifically designed for amaXhosa adult women living with HIV/AIDs with an average of less than seven years of education and reporting pain. The factors identified in Section 6.4.8 (p.144) as being associated with pain were specifically considered in the development of the programme. In addition, the intervention was designed to maximise acceptability, feasibility and sustainability by using a culturally acceptable model with low resource requirements. The programme was not designed for use in mixed gender groups as this may have presented a barrier to effective communication on certain topics in this cultural group (see discussion in Section 4.3.4.2, p.87). In addition, the programme was designed to be delivered in a resource poor environment with no need for specialist equipment. The English version of the workbook developed for the programme is presented in Appendix G. Specific components of the programme design are discussed below.

### 7.2.2.1 Peer led

Peer-led education programmes have been successfully implemented in diverse settings for diverse conditions<sup>282 301 313</sup> and are widely recommended for use in programmes designed for PLWHA<sup>314</sup>. Peer-leaders are commonly used in counselling and education programmes to overcome language and cultural barriers to care as well as to alleviate pressurised health care professionals<sup>301</sup>. In addition, peer-leaders act as models actively demonstrating the benefits of implementing the knowledge and skills being delivered through a programme or intervention<sup>312</sup>. Studies on peer-led programmes have reported them to be effective in increasing knowledge in PLWHA<sup>314</sup>. In addition, peer-led programmes are believed to lead to greater changes in behaviour than expert-led programmes based on social learning theory in particular<sup>315</sup>. The peer-led model was adopted to address language and cultural issues, minimise load on health care professionals and facilitate behaviour change through peer modelling.

#### 7.2.2.2 Educational material

A course workbook titled “Positive Living” (Appendix G) based on HIV/AIDS specific educational material developed by the Treatment Action Campaign<sup>316</sup>, and the Stanford Patient Education Research Centre<sup>308 317</sup>, and on chronic pain educational material<sup>318</sup> was developed. The workbook aimed to facilitate the development of the core self-management skills of problem solving, decision making, finding and utilizing resources, forming partnerships with health care professionals, and taking action<sup>312</sup>. To allow for a transfer of knowledge into action; in other words to facilitate skills acquisition, the handbook included an exercise diary , goal setting and problem solving tasks<sup>312</sup>.

The workbook was presented in six chapters; each chapter designed to be read consecutively and titled Week 1, Week 2 etc. to encourage users to work through the workbook at regular intervals. Each week focussed on a specific topic as presented in Table 7-1. At the end of each chapter, action planning forms based on the topic for the week were included in addition to an exercise diary. The final section of the workbook included information on resources and additional action planning and exercise sheets.

The workbook was initially developed in English. It was then translated into isiXhosa by a first language isiXhosa speaker who was familiar with the information contained and objectives of the programme. The English and Xhosa versions of the workbook were then provided to a third bilingual research assistant who reviewed the translated workbook to ensure accuracy and semantic equivalence in the Xhosa version.

Table 7-1: Topics and content of the “Positive Living” workbook

Topic for the Week	Content
Week 1: Self-management and Exercise	<ul style="list-style-type: none"> <li>• What is meant by “self-management”</li> <li>• Self-management steps</li> <li>• Action plans</li> <li>• Exercise</li> <li>• Types of exercise</li> <li>• Steps to success with exercise</li> <li>• An exercise routine</li> </ul>
Week 2: Managing common symptoms of HIV/AIDS	<ul style="list-style-type: none"> <li>• Symptom management</li> <li>• Action charts for common symptoms               <ul style="list-style-type: none"> <li>○ Coughing</li> <li>○ Depression</li> <li>○ Diarrhoea</li> <li>○ Fever</li> <li>○ Headache</li> <li>○ Eye</li> <li>○ Nausea and vomiting</li> <li>○ Shortness of breath</li> <li>○ Sore throat and mouth</li> <li>○ Skin problems</li> <li>○ Urination problems</li> </ul> </li> </ul>
Week 3: Stress Management	<ul style="list-style-type: none"> <li>• What is stress?</li> <li>• Managing stress</li> <li>• Sleep</li> <li>• Communication with your health carer</li> <li>• Relaxation skills</li> </ul>
Week 4: Pain	<ul style="list-style-type: none"> <li>• Causes of pain in HIV/AIDS</li> <li>• Pain self-management</li> </ul>
Week 5: Eating Well	<ul style="list-style-type: none"> <li>• Balance nutrition</li> <li>• Dealing with barriers to eating well</li> <li>• Food safety</li> </ul>
Week 6: Continuing as a successful self-manager	<ul style="list-style-type: none"> <li>• Action planning for the future</li> <li>• Reflection on changes</li> </ul>

### 7.2.2.3 Group work

Intervention programmes can be delivered in individual or group formats. Chronic disease and chronic pain management programmes commonly adopt a group approach for delivery of interventions with no differences having been found in effect between group and individual treatments<sup>319 320</sup>. The group approach has many advantages including providing support for group members through interaction and feedback, and, as mentioned previously, provides opportunity for vicarious learning and sharing of goals<sup>321</sup>. The advantages of group work have been described as the non-specific effects of treatment gained from patients being able to express themselves in a safe and non-threatening environment which is enhanced through the sharing of common experiences and challenges<sup>321</sup>. However, it should be noted that group work is not appropriate for all individuals and that there is a limit to the size of effective groups. Persons with cognitive impairment, significant mental health disorders or interpersonal problems may not benefit from group work and should be managed individually<sup>319</sup>. Group size is recommended to be limited to a maximum of 12 people to ensure that relationships can be developed and facilitation of discussion is possible. Education in larger groups tends to become more didactic as facilitators struggle to manage interactions. Group work is beneficial as a treatment and, when used with appropriately screened patients, is a cost-effective, effective treatment approach. This approach was therefore selected for the intervention programme.

### 7.2.2.4 Exercise

As discussed previously, aerobic and strength training forms of exercise are safe for use in PLWHA<sup>4 122-125 304 306 307</sup><sup>322</sup>. An aerobic exercise programme was developed using intervals of progressive strength training and stretching based on the American College of Sports Medicine Guidelines<sup>323</sup>. The exercises were chosen on the basis of safety, simplicity (no additional equipment required) and efficacy for increasing aerobic fitness and muscle strength. A full description of the exercise programme is included in the workbook (Appendix G). The exercise programme was started at 20 minutes in length at the first week and was designed to increase by 10% each week. Instructions for the exercises included in the workbook indicated that all aerobic exercises should be carried out according to the Borg Scale level of “somewhat hard”. This level of exertion has been found to consistently reflect an effort of 60% of maximum heart rate<sup>324</sup>. Stretching and strengthening exercises selected focused on muscle groups previously targeted in training programmes designed for PLWHA based on recognised patterns of deterioration<sup>122</sup>. The intervention was designed so that no exercises were conducted in the first session of the intervention to allow participants time for familiarisation. However, every subsequent session began with an initial 20 minutes of exercise, which was progressed weekly.

In addition to the practical component of exercise in the intervention programme, the workbook included exercise action planning forms and weekly exercise diaries to encourage participants to continue with an exercise schedule independently. Further, the chapter on exercise included information on exercise safety including when not to exercise due to symptoms of illness.

#### 7.2.2.5 Agreement of participation

An “Agreement of Participation” was developed for use by the participants (Appendix H). This agreement was designed to facilitate a discussion on the confidential nature of the workshops and to encourage commitment to attend at the first workshop. The discussion on the agreement was also designed to allow participants to introduce themselves and present any expectations or requests to the group. The agreement was designed to allow for specific items raised by participants to be added as required.

#### 7.2.2.6 Relaxation training

Relaxation is one of the most commonly used approaches in the treatment of chronic pain and is supported by a large body of literature<sup>132 325</sup>. In particular, relaxation strategies have been found to be effective for decreasing the frequency and intensity of attacks in chronic headache patients<sup>326</sup>. Considering that the head and neck regions were the most common sites of pain (Section 6.4.2, p.136), relaxation training was specifically included in the intervention. While the instruction to “relax” may be regarded as simple, the skill of relaxation is one which requires guided training and practice in order to master<sup>132</sup>. The intervention was designed to conclude every session with a guided relaxation session facilitated by the peer-leader with the aim of developing the skill. In addition, information on relaxation strategies and relaxation scripts were included in the workbook.

#### 7.2.2.7 Six –weeks

Chronic disease self-management and chronic pain self-management programmes commonly range from six to ten weeks in length<sup>204 205 208 296 312</sup>. Interventions lasting for longer periods of time have greater drop-out rates which may negatively affect outcome. A widely used patient education model is that developed by the Stanford Patient Education Research Centre where several peer-led chronic disease management programmes have been developed and tested in various cultural and disease groups<sup>313</sup>. In these programmes a time period of between six and seven weeks is used as this is regarded as the minimum time required to effect a change in behaviour while also being a period of time which is not regarded as excessively long by patients<sup>312</sup>. Based on this literature, a time period of six weeks was selected for the intervention programme based on this literature.

#### 7.2.2.8 Training and roll-out of the programme

Specific factors were considered for the roll-out of the intervention programme. These related to: identification and training of a peer-leader, maintaining the veracity of the intervention and venue for delivery of the programme.

In order for the intervention to be effective, the characteristics of a suitable peer-leader were considered. A peer-leader would need to be identified from the target community with suitable medical and social history. The peer-leader would need to be bilingual in English and isiXhosa to facilitate training and be literate in both languages. Training of the peer-leader would need to include theoretical training in material covered in the programme. In addition, training in the theory and practical of group exercise and relaxation techniques as well as screening for contraindications to exercise would need to be covered. Finally the peer-leader would need to be instructed in practical group facilitation skills, goal setting and activity scheduling. Considering these training needs, a minimum training time of 40 hours was proposed for both training and evaluation of theoretical and practical skills. This in-depth training using the developed workbook was also aimed at maintaining the veracity of the programme.

The venue selected for delivery of the programme had to be easily accessible to the community, be safe, sheltered and private. Venues could include community or religious halls, community health centres, and or schools outside of school hours.

Once the intervention programme had been developed, its effect on pain in amaXhosa women living with HIV/AIDS was tested.

## 7.3 The effects of a six-week peer-led exercise and education intervention

### 7.3.1 Aims and Objectives

The aim of this study was to test the six-week peer-led exercise and education intervention programme (Positive Living) designed to assist with the management of pain in amaXhosa women living with HIV/AIDS.

#### *Hypothesis:*

Participation in a custom designed six-week peer-led exercise and education intervention programme will decrease pain and its effects and improve function, health and quality of life in amaXhosa women living with HIV/AIDS.

#### 7.3.1.1 Objectives

The specific objectives with regard to amaXhosa women living with HIV/AIDS and reporting pain, included:

1. To determine whether there would be a significant difference in the scores of patients who received the intervention and a control group who received an education workbook, with regard to :
  - a. Pain severity and pain interference using the Brief Pain Inventory<sup>96</sup>.
  - b. Self-efficacy using the Self-efficacy for Managing Chronic Disease 6-item Scale Xhosa<sup>210</sup>
  - c. Health Related Quality of Life (HRQoL) using the EQ-5D- Xhosa<sup>145 263</sup>
  - d. Symptoms of depression using the Beck Depression Inventory<sup>246</sup>.
2. Establish whether the programme was feasible and acceptable based on respondents perceptions of the programme as expressed during guided interviews.

## 7.3.2 Method

### 7.3.2.1 Research design

A single blind randomised controlled trial was conducted.

### 7.3.2.2 Sample size

Sample size was calculated using Epi Info® (Version 7). As pain was the primary outcome measure of this study, change in pain severity scores on the BPI in response to intervention was selected to determine the required sample size. Sample size was calculated using a smallest meaningful difference of three, and a standard deviation of 1.57 based on a score of three out ten being the smallest clinically relevant change in pain<sup>217</sup> and the standard deviation obtained in the prevalence study (Chapter 5). With statistical significance set at  $p < 0.05$ , 14 participants per group would provide 95% probability of detecting a treatment difference of  $3 \pm 1.57$  in pain. Therefore, a minimum of 14 participants per group were required, a total of 28 participants. To allow for attrition, 38 participants (19 in each group) was the sample target.

### 7.3.2.3 Subjects

The participants were drawn from respondents identified in the prevalence study reported on in Chapter 5. Telephone calls were made over a two-week period to all participants who had reported pain ( $n = 170$ ). Numbers of participants recruited and reasons for exclusion are illustrated in Figure 7-1.

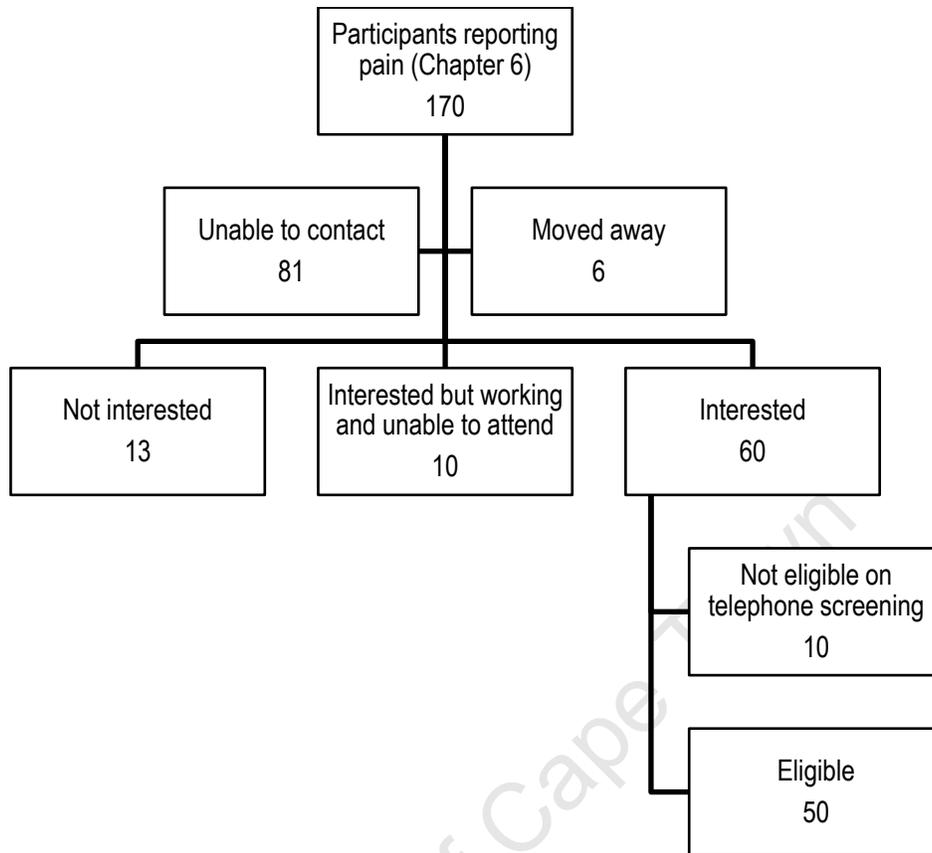


Figure 7-1: Telephonic recruitment of participants

Inclusion criteria used to telephonically screen for participants included: being HIV positive at any stage of the disease; and have responded “Yes” to the question: “Throughout our lives most of us have had pain from time to time (such as minor headaches, sprains, toothaches). Have you had pain other than these everyday kinds of pain during the last week?” on the Brief Pain Inventory in the study reported on in Chapter 6. Participants were excluded if they were found to be unfit to participate in exercise according to the American College of Sports Medicine (ACSM) guidelines.

Of the 60 participants who indicated interest in participating in the study, 10 were not eligible to participate in an exercise programme after screening with the ACSM Guidelines for Exercise as used by the Sport Science Institute of South Africa<sup>304 323</sup> (Appendix I). The 50 participants eligible for participation were invited to attend the clinic to initiate the study.

#### 7.3.2.4 Instrumentation

The primary outcome measure was the Brief Pain Inventory - Xhosa<sup>96</sup> described in Chapter 4 and used in Chapter 6. In addition to information on pain, data was collected using the instruments previously described (Chapter 4 and Chapter 5) and utilised in the prevalence study (Chapter 6):

1. Demographic questionnaire: demographic and personal characteristics including health status.
2. The Xhosa version of the Self-efficacy for Managing Chronic Disease 6-item Scale to describe levels of self-efficacy of the individual<sup>210</sup>.
3. EQ-5D Xhosa to describe the health related quality of life<sup>149</sup>.
4. Beck Depression Inventory in Xhosa<sup>246</sup>.

At the final interview, participants were asked three questions in an open guided interview to evaluate acceptability of the intervention or workbook. The three questions posed were:

1. What did you like about the workshops/workbook?
2. Was there anything you didn't like in the workshops/workbook?
3. Is there anything that you would to include or add in to the workshops/workbook?

#### 7.3.2.5 Intervention programme

The six-week peer-led exercise and education "Positive Living" programme described earlier was used as the basis for the intervention programme.

#### 7.3.2.6 Procedure

Ethical approval was obtained from both the Faculty of Health Sciences Health Ethics Committee of the University of Cape Town (REC Ref: 420 2007) and the Province of the Western Cape Department of Health (Ref: 19/18/RP12/2009) (Appendix B:).

The same research assistant (RA) employed for the study reported on in Chapter 6 was employed to recruit, screen and interview participants. The RA was blinded as to the allocation of participants to the control or experimental groups. In addition a peer-educator was recruited to lead the intervention programme. The peer-educator was identified through the Treatment Action Campaign and had previous training in peer-counselling and education through that organisation and had worked as a peer-counsellor in the community health centre maternity unit. The peer educator underwent training as described in Section 7.2.2 (p.173). To ensure that peer educator training was adequate and to ensure that the model of delivery was adhered to, the workshop sessions were monitored by the researcher through the use of video recordings at every session.

The procedure is illustrated in Figure 7-2. The participants contacted by telephone, willing to take part and screened for exercise using the ACSM guidelines (Figure 7-1) were invited to attend the physiotherapy department for baseline data collection and randomisation (Week 0). On arrival, participants were provided with information about the study in isiXhosa (English versions of information and consent forms are presented in Appendix J). Information included explanation of the process of randomisation to the intervention and control groups as well as the need to maintain the blinding of the RA. Participants who consented to take part and who fulfilled the inclusion criteria were then randomised to the experimental or control groups using random number allocation by the researcher to maintain blinding of the research assistant. Random numbers were generated using Microsoft Excel 2010 ®. The researcher requested participants allocated to the experimental group to return to the clinic the following week (Week 1) to participate in the intervention programme. Participants were randomly allocated to attend the intervention in one of two groups to control for group size. Participants in the control group were provided with workbooks and appointments to return in four weeks for follow up interviews.

All participants in the study (both experimental and control groups) were provided with an English and isiXhosa version of the intervention workbook. Mobile telephone numbers were obtained from every participant to allow for the sending of reminder messages regarding the intervention and for follow up appointments. All participants were provided with appointment cards with the date and time of the next appointment recorded. The contact telephone number of the researcher was included on the appointment card. An amount of R30 was provided to every person attending the clinic at every visit to cover travel expenses. At the final session of the intervention, participants in the experimental group were presented with a certificate of completion (Appendix K).

Follow up interviews conducted by the blinded RA took place at Weeks 4, 8, 12 and 16. Interview appointments were recorded on the appointment card and participants were reminded of their appointments by short messenger service (sms) via their cellular telephones on the day before the appointment and again on the morning of the appointment. Participants who did not arrive for their appointment were followed up through telephone calls and tracing clinic records. Participants, who were out of town when interviews were scheduled, were interviewed over the telephone.

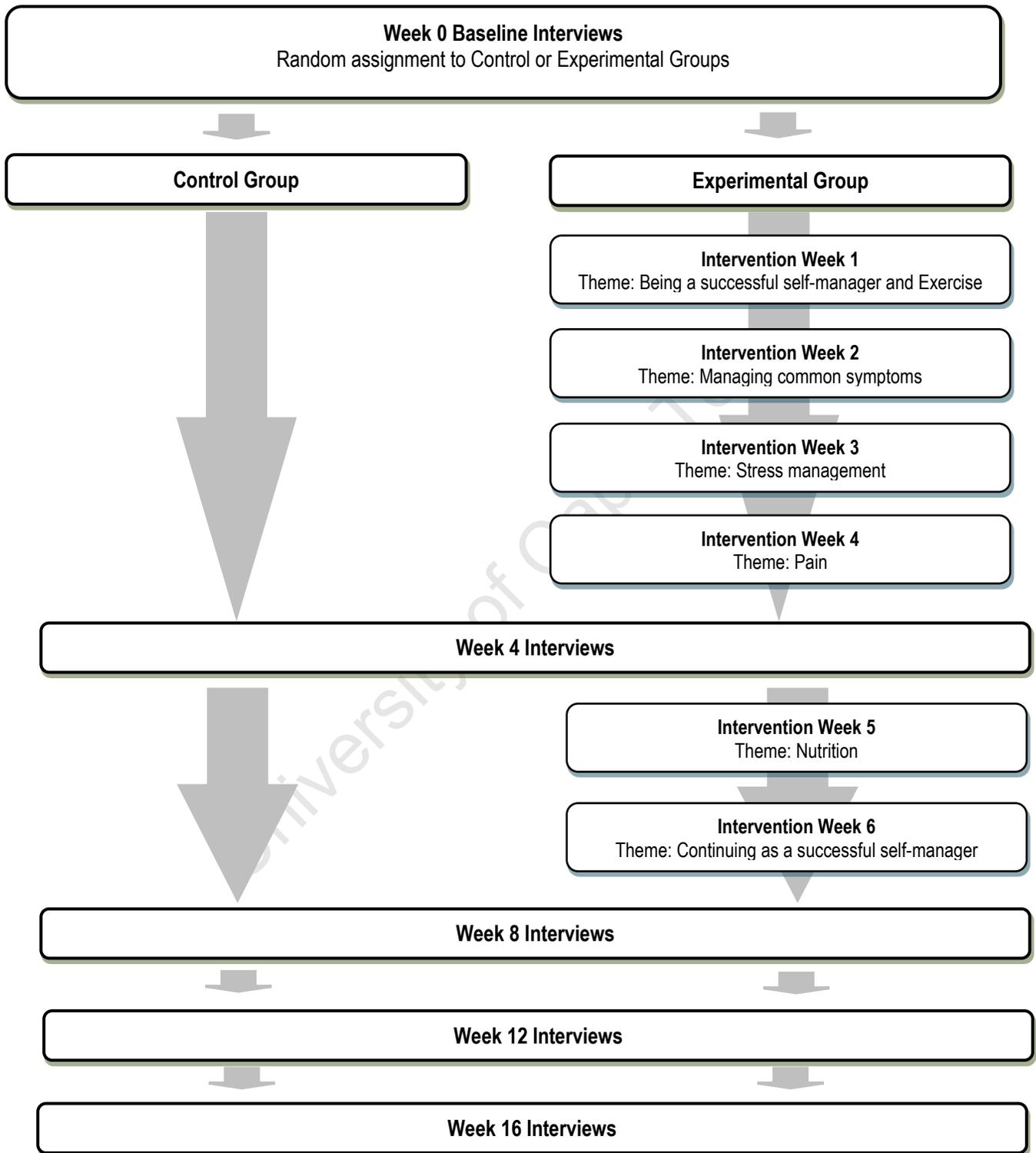


Figure 7-2: Timeline of assessment and intervention procedure

#### 7.3.2.7 Ethical considerations

All participants were provided with an information sheet in their first language (Appendix J) and the opportunity to clarify any questions was provided prior to obtaining signed informed consent. Confidentiality of the data obtained was assured.

Confidentiality was maintained through the use of patient numbering. Those who choose not to participate in the study were reassured that this in no way affected their future treatment or access to care. Should a participant's name need to be released in order to refer them for further assessment or treatment, the participant's consent would be obtained. All participant records were and continue to be kept secure. All reports on the study will maintain participant confidentiality.

There was a small risk from participating in exercise as part of the study. Risk was minimised by screening of participants and training of the facilitator in health screening questions and observational skills for use during exercise sessions. In addition guidelines on safety in exercise were included in the workbook.

There were several possible benefits from the study. Patients completed a battery of questionnaires which although not diagnostic could indicate the need for intervention. Participants who were identified to be at risk of mental health disorders following administration of the BDI were referred to the appropriate mental health services for management. Participants who were identified with disability were referred to the appropriate services. In the light of the seriousness of the HIV epidemic, information on referral to HIV centres was included in a list of references in the workbook.

#### 7.3.2.8 Data Analysis

Data were analysed using Statistica software (StatSoft, Inc. 2004. STATISTICA, Data Analysis Software System, Version 10. [www.statsoft.com](http://www.statsoft.com)). The Mann-Whitney U and Chi-squared ( $\chi^2$ ) tests were used to determine differences in socio-economic, demographic and clinical characteristics of the experimental and control groups. The  $\chi^2$  test was used to analyse for change in prevalence of pain. Statistical significance for the two main effects of group and time, and the interaction (group x time) for pain severity, pain interference, self-efficacy, HRQoL and depression were assessed using a two-way analysis of variance (ANOVA) with repeated measures. Tukey's post hoc comparisons were performed where necessary. Analysis was by intention to treat. Missing data was managed by carrying forward the last observed measurement. All data are presented as the mean  $\pm$  standard deviation. Statistical significance was accepted as  $p < 0.05$ .

### 7.3.3 Results

The sample will first be described followed by presentation of the descriptive data. In the final section of the results, analysis of changes in variables over time will be presented followed by presentation of the responses to the guided interviews.

#### 7.3.3.1 Socio-economic, demographic and clinical characteristics of the participants (N = 27)

Of the 170 women who reported pain in Phase 1 of the study, 27 were ultimately recruited for the intervention study and were randomly assigned to the Experimental Group (n = 12) to participate in the intervention programme or the Control Group (n = 15) (Figure 7-3). One participant was not accepted into the study due to a mild intellectual disability.

The study was run over a 16 week period from September 2011 to December 2011. The participants were recruited to the study reported in Chapter 6 in 2010. The mean time since interview in the first study in 2010 for the entire sample was  $15 \pm 2.97$  months (Range 9 – 22). There was no difference in time since interview in 2010 and recruitment to the intervention study in 2011 between the experimental group ( $15 \pm 3.29$  months) and the control group ( $15.01 \pm 2.01$  months;  $t = 0.13$ ,  $p = 0.89$ ).

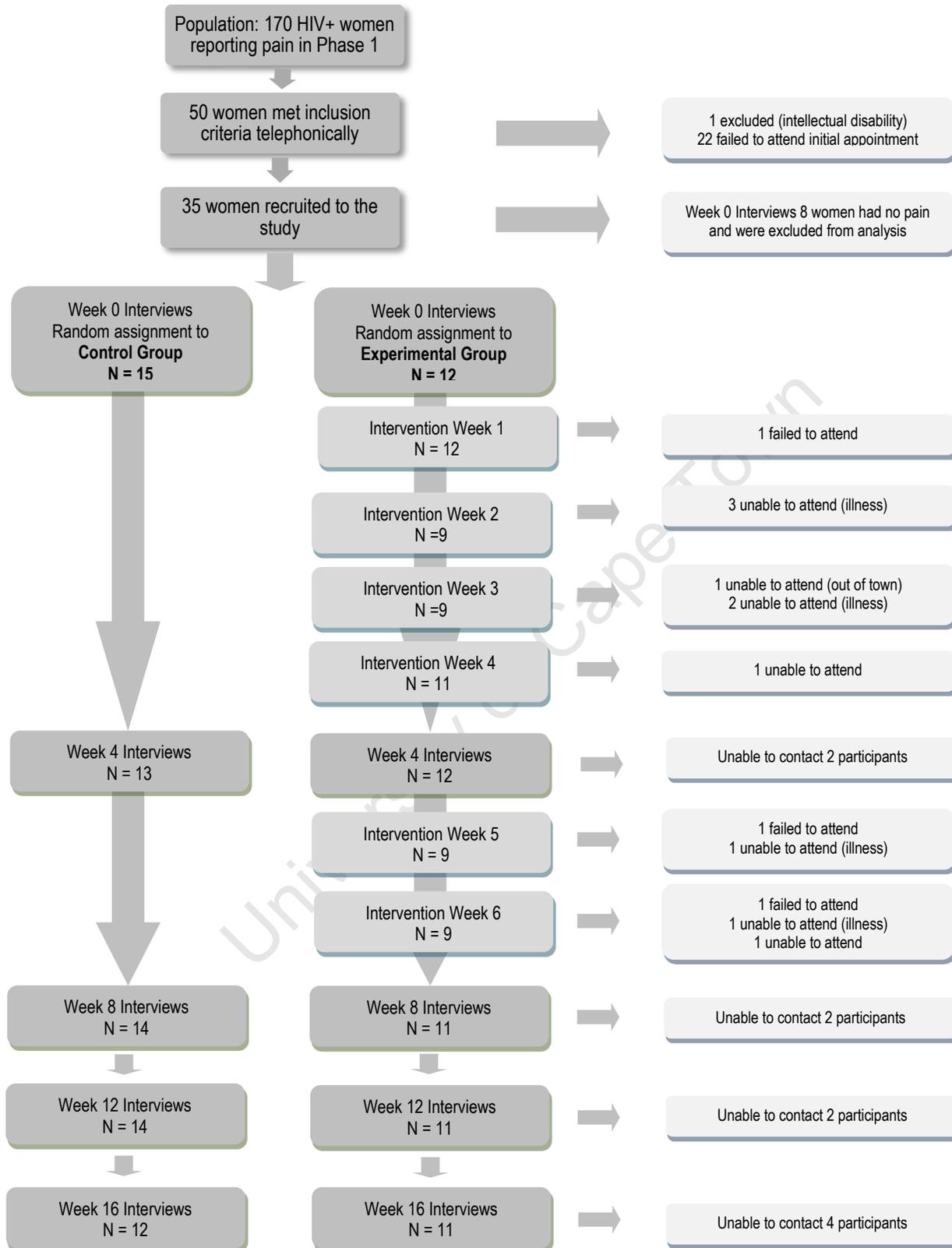


Figure 7-3: Sampling and data collection process

*Socio-economic characteristics of the participants*

Results are presented for the sample (N = 27), the experimental group (n = 12), and the control group (n = 15). There were no significant differences between groups for age, the number of languages participants were able to speak or write or educational level (Table 7-2).

Table 7-2: Age, number of languages and level of education of the participants (N = 27)

	Participants	Experimental Group	Control Group	
	Mean ± SD (Range)	Mean ± SD (Range)	Mean ± SD (Range)	Significance Test
<b>Age</b>	N = 27	n = 12	n = 15	
Years	30.8 ± 4.5 (20 – 39)	32 ± 4.1 (22 – 37)	29.9 ± 4.7 (20 – 39)	U = 59.5; p = 0.14
<b>Languages</b>	N = 27	n = 12	n = 15	
Number of spoken languages	2.3 ± 0.6 (1 – 4)	2 ± 0.7 (1 – 4)	2.5 ± 0.5 (2 – 3)	U = 62.5; p = 0.19
Number of written languages	2.1 ± 0.6 (1 – 4)	2 ± 0.8 (1 – 4)	2.1 ± 0.4 (2 – 3)	U = 81; p = 0.68
<b>Educational Level</b>	N = 27	n = 12	n = 15	
Number of years in school	10.5 ± 1.4 (8 – 12)	10.3 ± 1.6 (7 – 12)	10.7 ± 1.16 (9 – 12)	U = 75; p = 0.48

There were also no differences in employment status, or marital status between those in the experimental group and the control group (Table 7-3).

Table 7-3: Employment and marital status of the participants (N = 27)

	Participants	Experimental Group	Control Group	Significance Test
	Number (%)	Number (%)	Number (%)	
<b>Employment Status</b>	N = 27	n = 12	n = 15	$\chi^2 = 4.39$ ; p = 0.50
Unemployed	12 (45)	5 (42)	7 (47)	
Unemployed – receiving a disability grant	5 (19)	3 (25)	2 (13)	
In formal employment	5 (19)	1 (8)	4 (27)	
Homemaker/domestic worker	3 (11)	2 (2)	1 (7)	
Self-employed	0 (0)	0 (0)	0 (0)	
Working or has worked in health or social welfare	1 (4)	0 (0)	1 (7)	
Missing	1 (4)	1 (8)	0 (0)	
<b>Marital Status</b>	N = 27	n = 12	n = 15	$\chi^2 = 3.21$ ; p = 0.2
Single	18 (67)	6 (50)	12 (80)	
Partner/Married	8 (30)	5 (42)	3 (20)	
Widowed	1 (4)	1 (8)	0 (0)	

There was no difference between groups in current smoking or alcohol consumption. However there were differences in past smoking with six participants in the control group having previously smoked compared with none who had previously smoked in the experimental group ( $\chi^2 = 6.17$ ; p = 0.01). There were no differences in previous alcohol use (Table 7-4).

Table 7-4: Current and past smoking and alcohol consumption (N = 27)

	Participants	Experimental Group	Control Group	
	Number (%)	Number (%)	Number (%)	Significance Test
<b>Smoking</b>	N = 27	n = 12	n = 15	$\chi^2= 6.17; p = 0.01$
Currently smoking	0 (0)	0 (0)	0 (0)	
Previously smoked	6 (22)	0 (0)	6 (33)	
Never smoked	21 (78)	12 (100)	9 (67)	
<b>Alcohol consumption - Current</b>	N = 27	n = 12	n = 15	$\chi^2= 1.29; p = 0.25$
Not currently consuming alcohol	26 (96)	11 (92)	15 (100)	
Currently consuming alcohol	1 (4)	1 (8)	0 (0)	
<b>Alcohol consumption – Previous</b>	N = 27	n = 12	n = 15	$\chi^2= 1.08; p = 0.3$
Previously never consumed alcohol	15 (56)	8 (53)	7 (47)	
Previously consumed alcohol	12 (44)	4 (27)	8 (53)	

*Clinical Characteristics of the Participants (N = 27)*

As per the inclusion criteria, all participants in the study were HIV positive. There were no differences in the clinical markers of the experimental group compared with the control group at baseline (data collected in the study 15 months previous – Appendix L).

At Week 0, there was no difference in HIV/AIDS stage when analysed by Stages I – IV ( $\chi^2= 2.34; p = 0.5$ ) or when collapsed and analysed as HIV+ (Stages I and II) and AIDS (Stages III and IV) ( $\chi^2= 1.42; p = 0.23$ ). There was no difference in management of the participants at recruitment into the intervention study (Table 7-5).

Table 7-5: HIV/AIDS management of the participants at recruitment into Phase II (Week 0) (N=27)

	Participants	Experimental Group	Control Group	
	Frequency (%)	Frequency (%)	Frequency (%)	Significance Test
<b>Clinical Stage (I – IV):</b>	N = 27	n = 12	n = 15	$\chi^2= 1.42; p = 0.23$
HIV= (Stages I and II)	8 (30)	2 (16.7)	6 (40)	
AIDS (Stages III and IV)	18 (67)	9 (75)	9 (60)	
Missing	1 (4)	1 (8.3)	0 (0)	
<b>Treatment:</b>	N = 27	n = 12	n = 15	$\chi^2= 6.59; p = 0.09$
First Line ARVs	19(70)	9(75)	10 (67)	
Second Line ARVs	5 (19)	2(17)	0 (0)	
Monitoring	4 (15)	0 (0)	4 (3)	
Pregnancy prophylaxis	1 (4)	0 (0)	1 (7)	
Missing	1(4)	1 (8)	0 (0)	

The ARV d4T which is known to be associated with the development of painful peripheral neuropathies was being used by four of the participants when interviewed for the study in 2010 (Baseline) and two participants at Week 0. Three of the participants in the experimental group were on d4T at Baseline and two remained on d4T at Week 0. In the control group, only one participant was on d4T at Baseline and she had been removed off the drug at Week 0. There was no difference between groups. At Week 0 one participant, a member of the control group, presented with an opportunistic infection for which she had initiated treatment (Pulmonary Tb).

### 7.3.3.2 Change in pain

All the participants in the intervention trial reported that they had pain in the study conducted in 2010 (Baseline) and at Week 0 (100% prevalence of pain). There were no differences between groups in the prevalence of pain at Weeks 4 ( $\chi^2= 0.14; p = 0.71$ ), 8 ( $\chi^2= 2.22; p = 0.14$ ), 12 ( $\chi^2= 0.27; p = 0.6$ ) and 16 ( $\chi^2= 2.7; p = 0.1$ ) (Figure 7-4). There was a significant reduction in the overall prevalence of pain for the sample from 100% at Week 0 to 22% at Week 16 ( $p < 0.01$ ) (Figure 7-5).

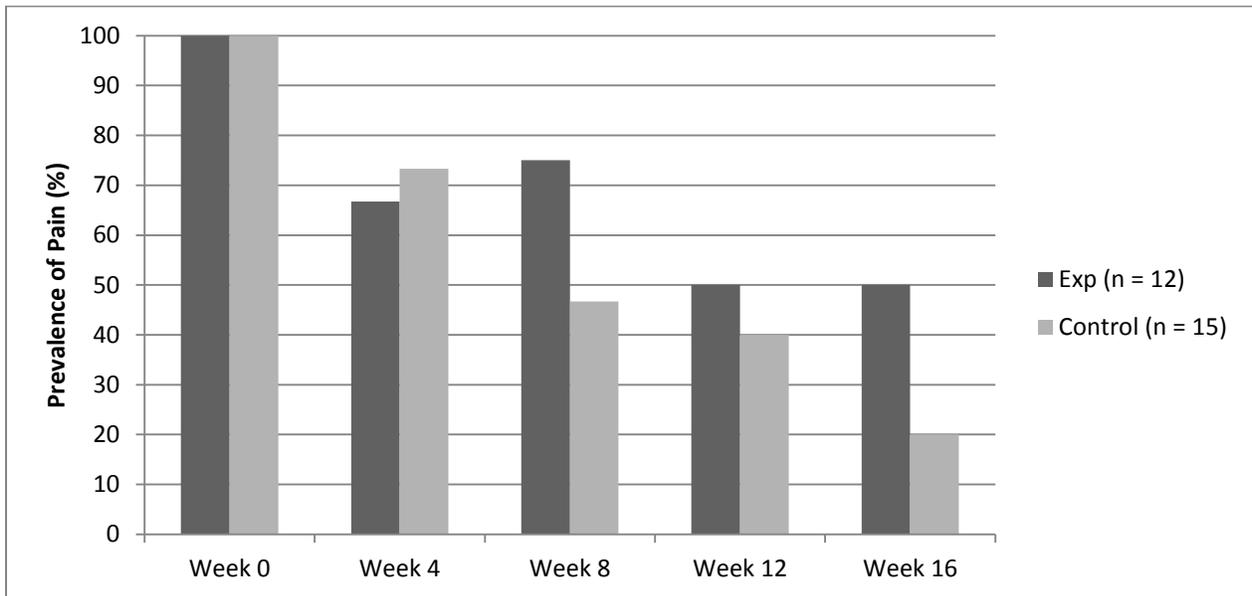


Figure 7-4: Change in prevalence of pain in the experimental and control groups over time (N = 27)

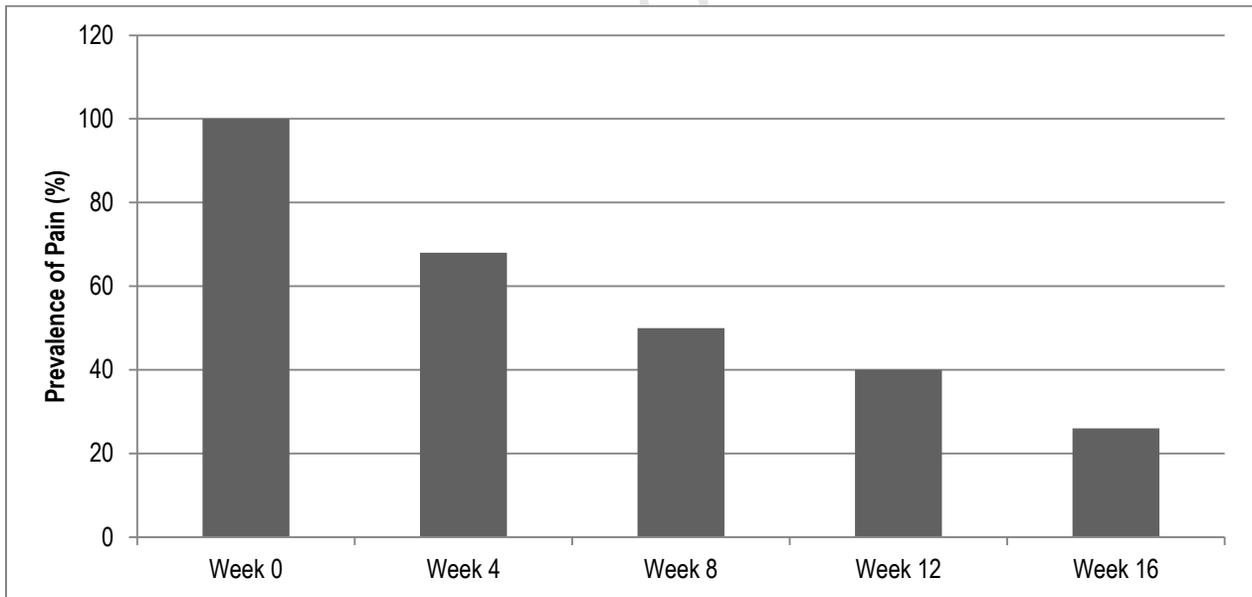


Figure 7-5: Change in prevalence of pain for the sample (N = 27)

### Pain Severity Scores (PSS)

Pain Severity Scores (PSS) and Pain Interference Scores (PIS) are presented in (Table 7-6). There were no significant differences between groups in Pain Severity Scores (PSS) over the 16 weeks of the study ( $F_{(5-125)} = 0.93$ ;  $p = 0.46$ ) but there was a significant difference in PSS over time ( $F_{(5-125)} = 12.05$ ;  $p < 0.01$ ) (Figure 7-6). There was no improvement in PSS between Baseline ( $5.32 \pm 1.93$ ) and Week 0 ( $5.55 \pm 1.65$ ). PSS improved significantly between Week 0 and Week 4 ( $3.81 \pm 2.89$ ,  $p = 0.04$ ), Week 8 ( $3.81 \pm 3.03$ ;  $p < 0.01$ ); Week 12 ( $2.79 \pm 3.38$ ;  $p < 0.01$ ) and Week 16 ( $1.81 \pm 2.87$ ;  $p < 0.01$ ). PSS improved significantly between Week 4 and Week 16 ( $p = 0.04$ ). In addition, PSS improved significantly between Baseline and Week 8 ( $p < 0.01$ ); Week 12 ( $p < 0.01$ ) and Week 16 ( $p < 0.01$ ).

Table 7-6: PSS and PIS for the participants, experimental and control groups at each time point (N = 27)

	Participants	Experimental Group	Control Group
	Mean $\pm$ SD	Mean $\pm$ SD	Mean $\pm$ SD
<b>Baseline</b>	N = 27	n = 12	n = 15
PSS	5.32 $\pm$ 1.93	4.9 $\pm$ 1.85	5.67 $\pm$ 1.98
PIS	6.3 $\pm$ 2.39	6.83 $\pm$ 2.66	5.87 $\pm$ 2.48
<b>Week 0</b>			
PSS	5.55 $\pm$ 1.65	6.06 $\pm$ 1.19	5.13 $\pm$ 1.88
PIS	6.39 $\pm$ 1.87	7.21 $\pm$ 2.15	5.73 $\pm$ 1.35
<b>Week 4</b>			
PSS	3.81 $\pm$ 2.89	3.94 $\pm$ 3.22	3.70 $\pm$ 2.72
PIS	3.94 $\pm$ 3.39	4.2 $\pm$ 3.64	3.73 $\pm$ 3.28
<b>Week 8</b>			
PSS	3.1 $\pm$ 3.03	3.67 $\pm$ 2.86	2.65 $\pm$ 3.19
PIS	3.21 $\pm$ 3.13	3.65 $\pm$ 2.93	2.85 $\pm$ 3.35
<b>Week 12</b>			
PSS	2.79 $\pm$ 3.38	2.96 $\pm$ 3.28	2.65 $\pm$ 3.57
PIS	2.38 $\pm$ 3.06	2.93 $\pm$ 3.35	1.94 $\pm$ 2.86
<b>Week 16</b>			
PSS	1.81 $\pm$ 2.87	2.71 $\pm$ 3.21	1.1 $\pm$ 2.45
PIS	1.89 $\pm$ 3.06	2.71 $\pm$ 3.39	1.23 $\pm$ 2.71

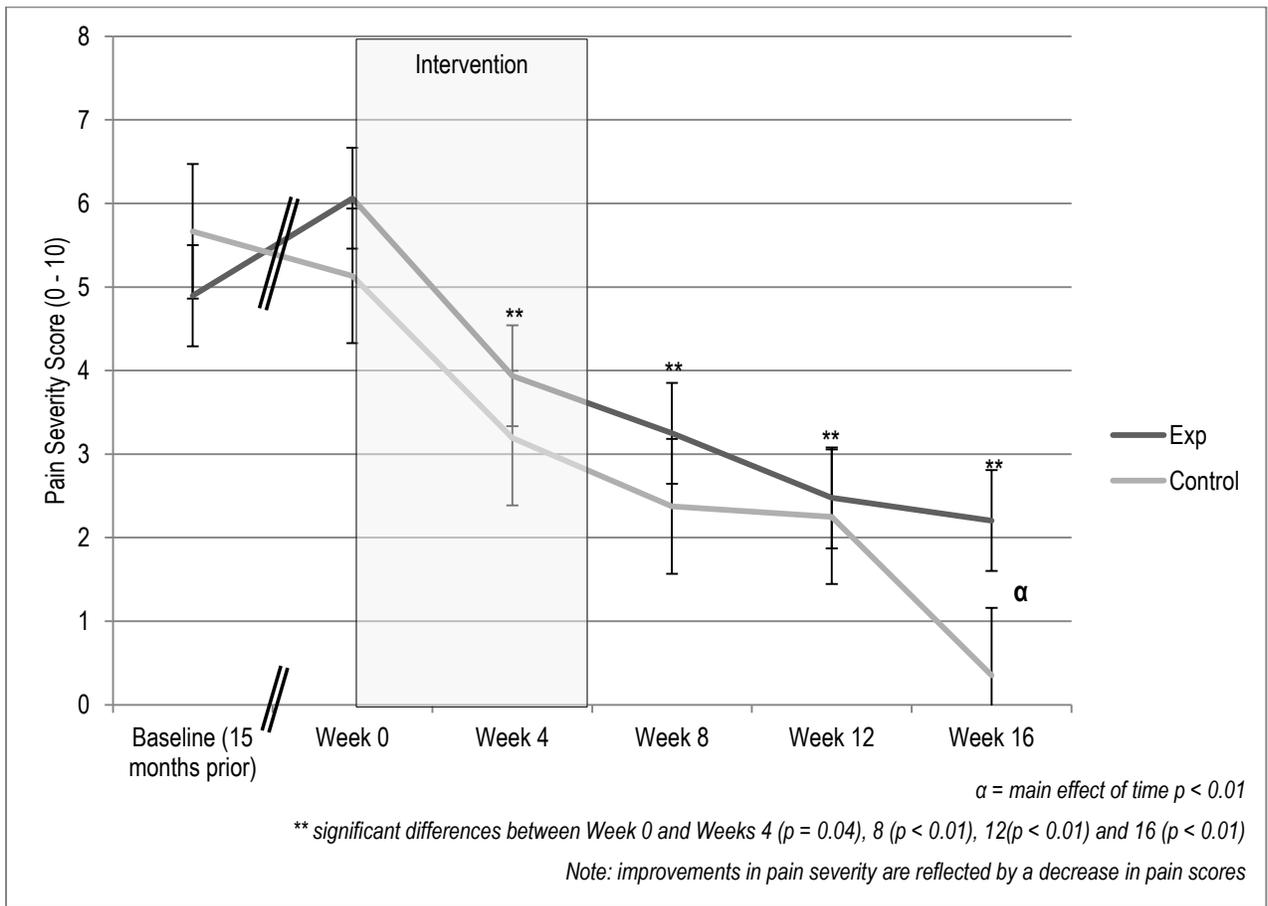


Figure 7-6: Change in Pain Severity Scores over time (N = 27)

### Pain Interference Scores (PIS)

There were no significant differences between groups in Pain Interference Scores (PIS) over the 16 weeks of the study ( $F_{(5-125)} = 0.2$ ;  $p = 0.98$ ) but there was a significant difference in PIS over time ( $F_{(5-125)} = 19.04$ ;  $p < 0.01$ ) (Figure 7-7). There was no improvement in PIS between Baseline ( $6.3 \pm 2.39$ ) and Week 0 ( $6.39 \pm 1.87$ ); (Table 7-6, p. 188). PIS improved significantly between Week 0 and Week 4 ( $3.78 \pm 3.45$ ;  $p < 0.01$ ); Week 8 ( $2.79 \pm 2.86$ ;  $p < 0.01$ ); Week 12 ( $2.1 \pm 2.92$ ;  $p < 0.01$ ) and Week 16 ( $1.37 \pm 2.66$ ;  $p < 0.01$ ). PIS improved significantly between Week 4 and Week 16 ( $p = 0.01$ ). In addition, PIS improved significantly at Weeks 4, 8, 12 and 16 (all  $p < 0.01$ ) compared to Baseline.

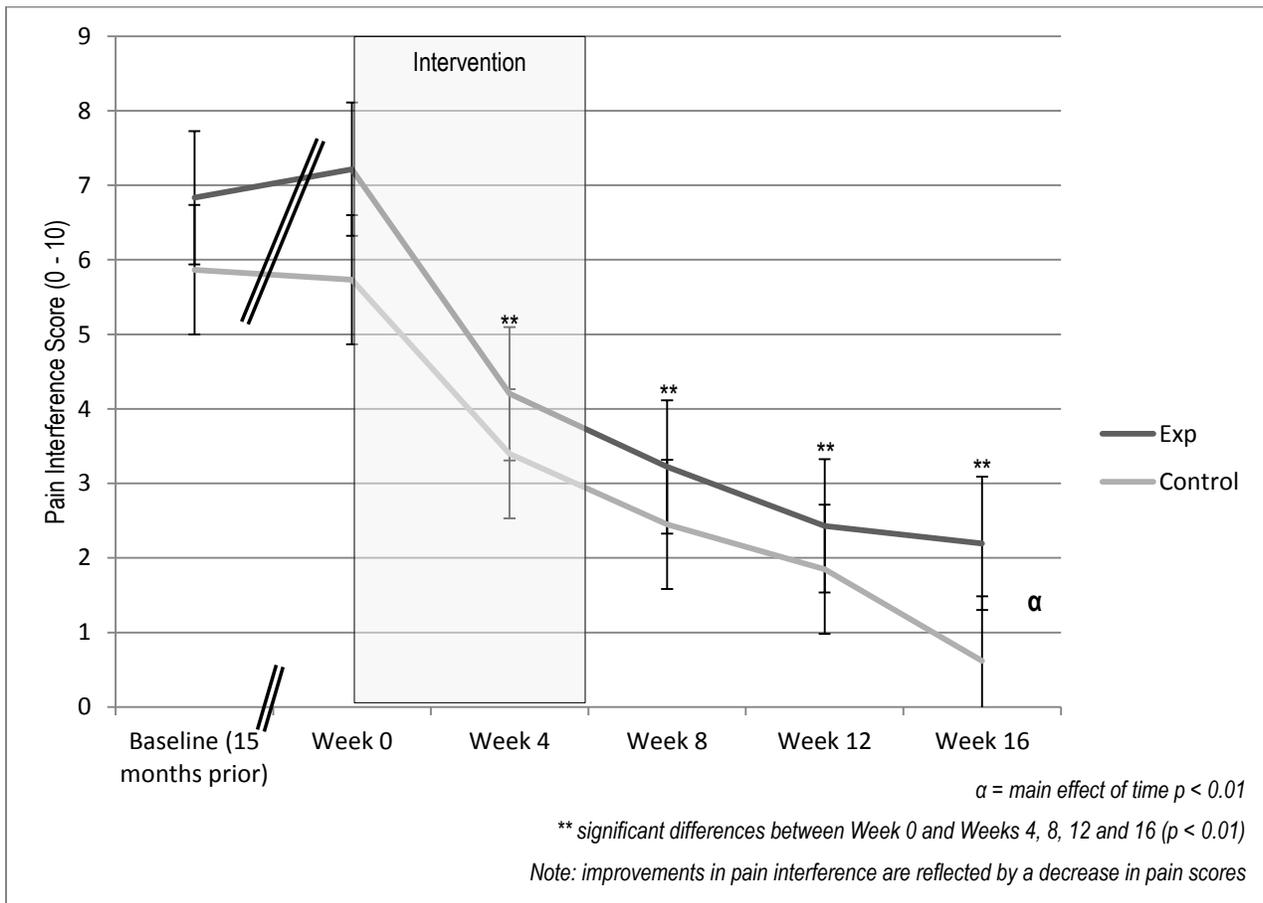


Figure 7-7: Change in Pain Interference Scores over time (N = 27)

### Pain Management Index (PMI)

There were no significant differences between groups in PMI over the 16 weeks of the study but there was a significant difference in PMI over time ( $F_{(5-125)} = 7.24$ ;  $p < 0.01$ ) (Figure 7-8). There was no improvement in the Pain Management Index for the participants between Baseline ( $-1.7 \pm 0.54$ ) and Week 0 ( $-1.67 \pm 0.62$ ). The PMI improved significantly between Week 0 and Week 12 ( $-0.64 \pm 0.99$ ;  $p < 0.01$ ) and Week 0 and Week 16 ( $-0.35 \pm 0.94$ ;  $p < 0.01$ ). The PMI improved significantly between baseline and Week 12 ( $-1.7 \pm 0.54$  vs.  $-0.64 \pm 0.99$ ;  $p < 0.01$ ) and Baseline and Week 16 ( $-1.7 \pm 0.54$  vs.  $-0.35 \pm 0.94$ ;  $p < 0.01$ ).

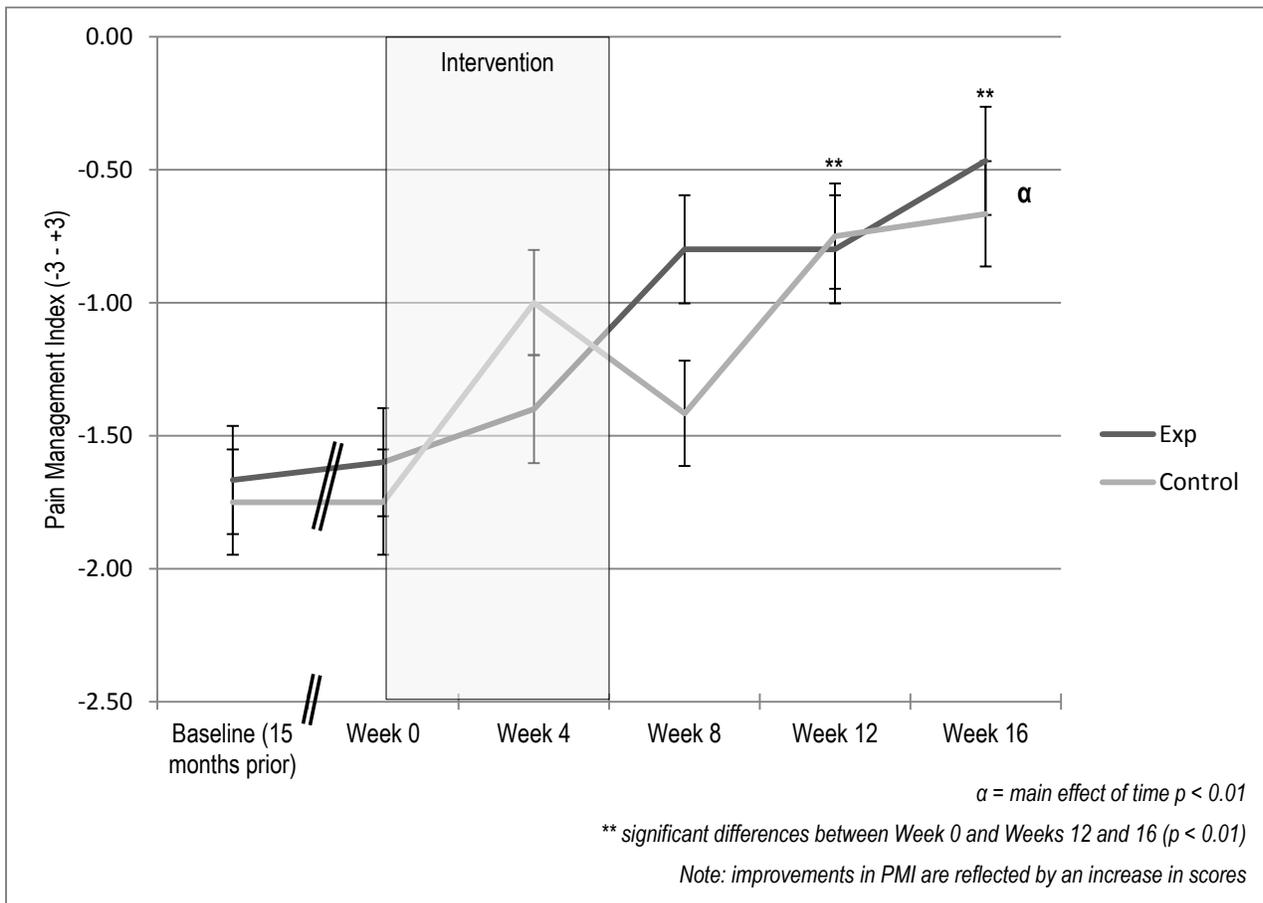


Figure 7-8: Change in Pain Management Index from Baseline to Week 16 (N = 27)

### 7.3.3.3 Self-efficacy (N = 27)

There were no significant differences between groups in self-efficacy scores (SE) over the 16 weeks of the study ( $F_{(5-125)} = 1.79$ ;  $p = 0.12$ ) (Table 7-7).

Table 7-7: Self-efficacy scores for participants at each time point (N = 27)

	Participants	Experimental Group	Control Group
	Mean $\pm$ SD	Mean $\pm$ SD	Mean $\pm$ SD
<b>Baseline</b>	N = 27	n = 12	n = 15
	7.09 $\pm$ 1.58	7.57 $\pm$ 1.29	6.7 $\pm$ 1.73
<b>Week 0</b>			
	7.19 $\pm$ 1.31	7.15 $\pm$ 1.35	7.21 $\pm$ 1.32
<b>Week 4</b>			
	7.38 $\pm$ 1.59	7.67 $\pm$ 1.65	7.15 $\pm$ 1.55
<b>Week 8</b>			
	7.61 $\pm$ 1.52	7.54 $\pm$ 1.53	7.67 $\pm$ 1.57
<b>Week 12</b>			
	7.90 $\pm$ 1.44	7.78 $\pm$ 1.74	7.99 $\pm$ 1.2
<b>Week 16</b>			
	8.07 $\pm$ 1.43	7.64 $\pm$ 1.54	8.41 $\pm$ 1.28

There was a significant difference in SE over time ( $F_{(5-125)} = 2.86$ ;  $p = 0.02$ ) (Figure 7-9). There was no improvement in SE between Baseline (7.09  $\pm$  1.58) and Week 0 (7.19  $\pm$  1.31). SE improved significantly at Week 16 (8.07  $\pm$  1.43;  $p = 0.04$ ) compared to Week 0. In addition, SE improved significantly between Baseline and Week 16 ( $p = 0.02$ ).

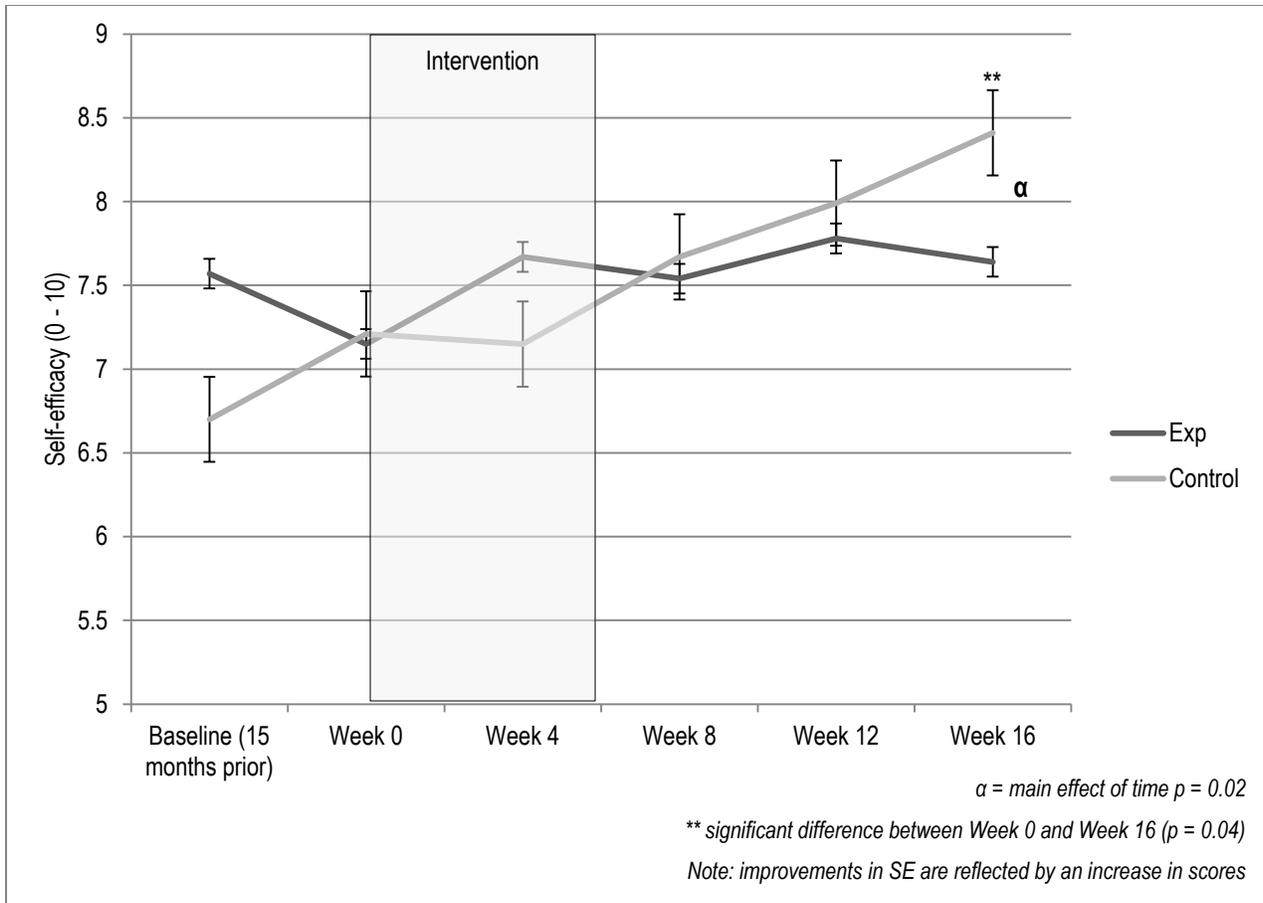


Figure 7-9: Change in Self-efficacy over time (N = 27)

#### 7.3.3.4 HRQoL (N = 27)

There were no significant differences between groups in scores for health related quality of life on the EQ VAS ( $F_{(5-125)} = 0.4$ ;  $p = 0.85$ ) or for the EQ-5D index ( $F_{(5-125)} = 0.36$ ;  $p = 0.87$ ) over the 16 weeks of the study (Table 7-8).

Table 7-8: EQ VAS Scores and EQ-5D Index scores at each time point (N = 27)

	Participants	Experimental Group	Control Group
	Mean ± SD	Mean ± SD	Mean ± SD
<b>Baseline</b>	N = 27	n = 12	n = 15
EQ VAS	66.67 ± 16.64	60 ± 11.28	72 ± 18.59
EQ-5D index	0.61 ± 0.34	0.53 ± 0.32	0.67 ± 0.35
<b>Week 0</b>			
EQ VAS	73.70 ± 19.64	70 ± 24.49	76.67 ± 14.96
EQ-5D index	0.76 ± 0.22	0.71 ± 0.17	0.79 ± 0.25
<b>Week 4</b>			
EQ VAS	83.60 ± 13.19	81.67 ± 12.67	85.38 ± 13.91
EQ-5D index	0.84 ± 0.17	0.83 ± 0.15	0.85 ± 0.19
<b>Week 8</b>			
EQ VAS	84.80 ± 13.27	81.82 ± 12.5	87.14 ± 13.83
EQ-5D index	0.91 ± 0.1	0.87 ± 0.10	0.95 ± 0.1
<b>Week 12</b>			
EQ VAS	80 ± 23.98	78.18 ± 20.4	81.43 ± 27.13
EQ-5D index	0.9 ± 0.13	0.86 ± 0.16	0.93 ± 0.1
<b>Week 16</b>			
EQ VAS	83.91 ± 17.77	82.73 ± 16.79	85 ± 19.31
EQ-5D index	0.92 ± 0.11	0.89 ± 0.11	0.94 ± 0.1

There was a significant difference in EQ VAS over time ( $F_{(5-125)} = 5.19$ ;  $p < 0.01$ ) (Figure 7-10). There was no improvement in EQ VAS between Baseline and Week 0 or between Week 0 and Weeks 4, 8, 12, and 16. EQ VAS improved significantly between Baseline and Week 4 ( $p < 0.01$ ); Week 8 ( $p < 0.01$ ); and Week 16 ( $p < 0.01$ ).

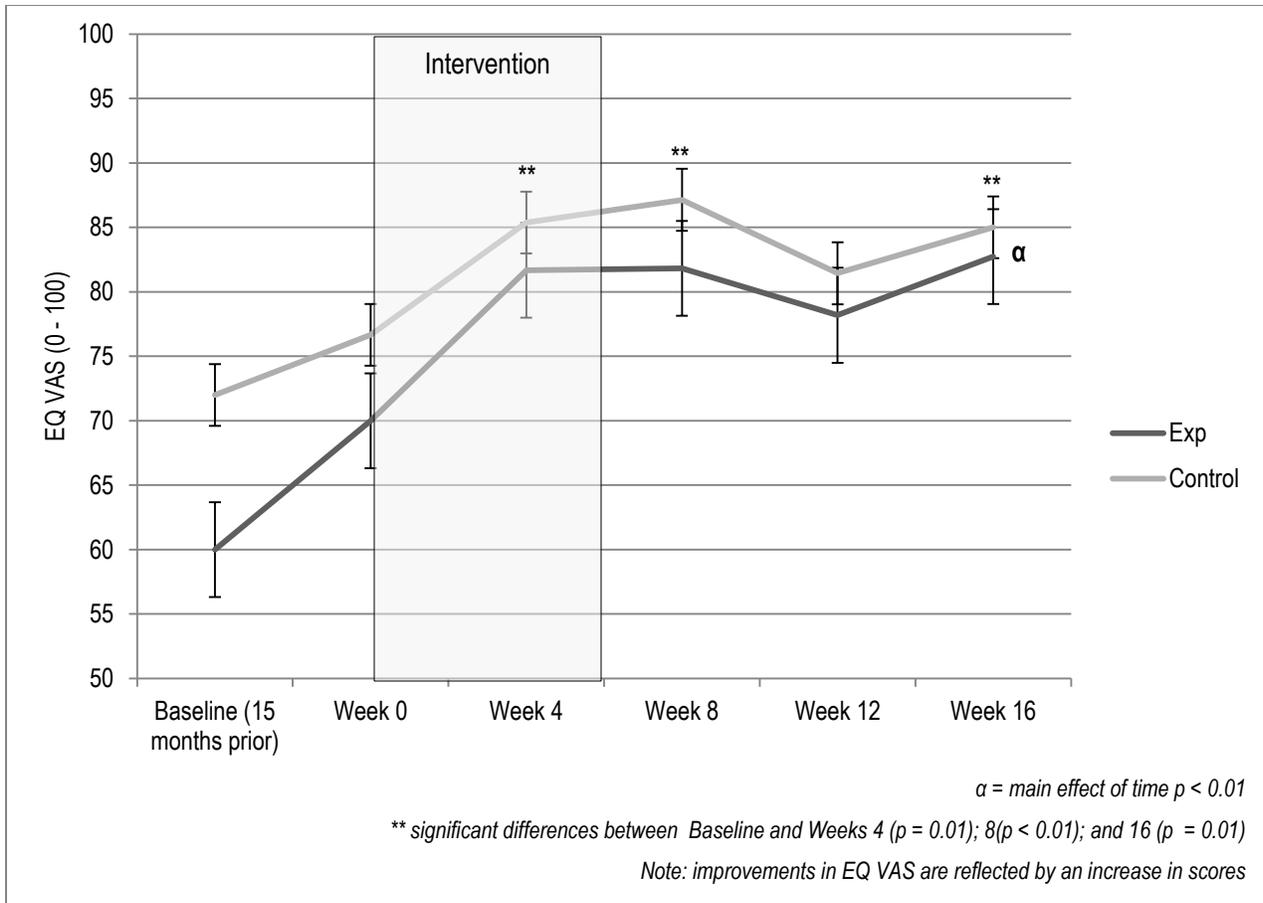


Figure 7-10: Change in EQ VAS scores over time (N = 27)

There was a significant difference in EQ-5D index over time ( $F_{(5-125)} = 15.18$ ;  $p < 0.01$ ) (Figure 7-11). There were significant improvements between Week 0 and Week 8 ( $p = 0.01$ ); Week 12 ( $p = 0.02$ ) and Week 16 ( $p < 0.01$ ). There were significant improvements in EQ-5D index between Baseline and all time points ( $p < 0.01$ ).

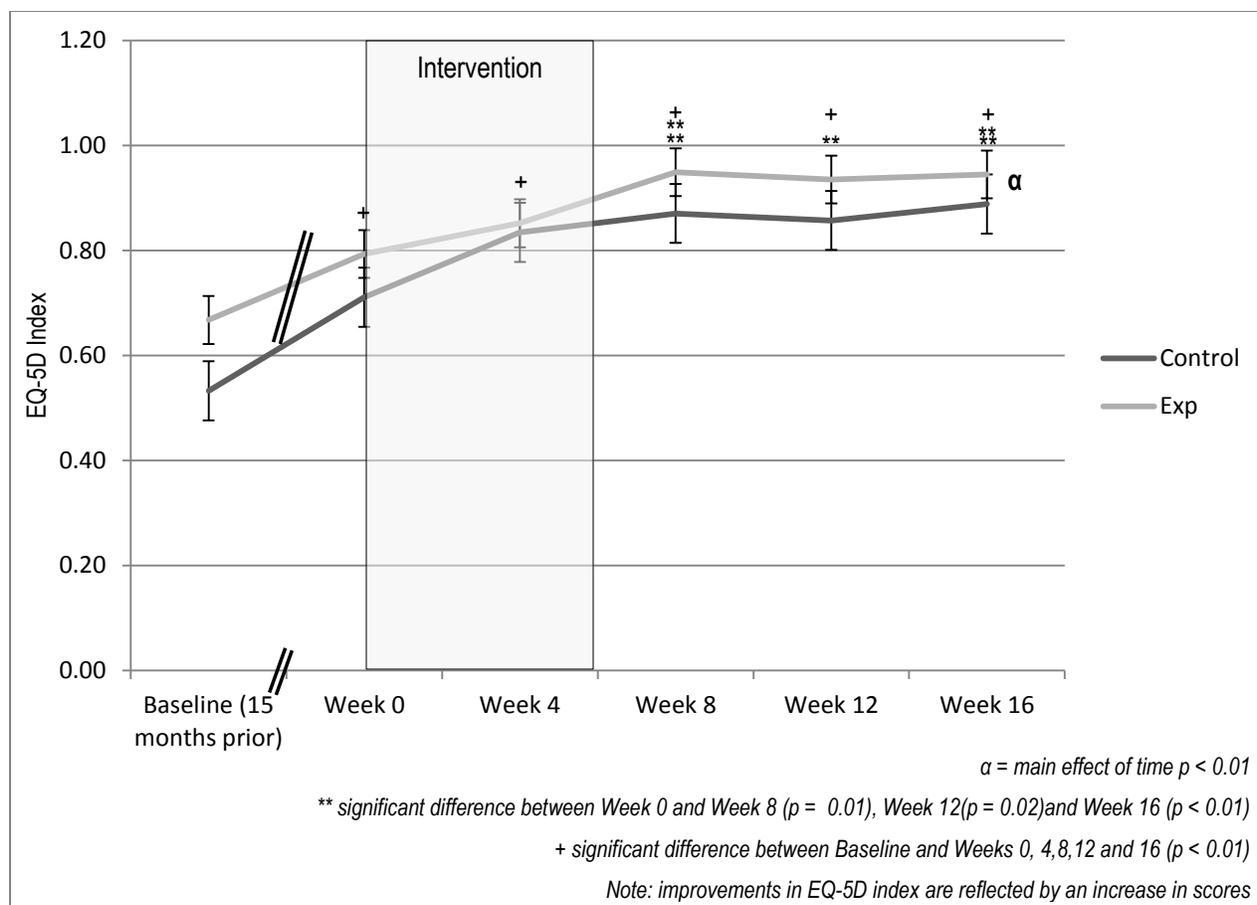


Figure 7-11: Change in EQ-5D index over time (N = 27)

Analysis of the five categorical sub-categories of the EQ-5D index was performed using chi-squared testing for categorical data. There were no differences between groups at any of the time points for the categories of mobility, self-care, usual activities or anxiety/depression. For pain/discomfort, there was a significant difference between groups at Week 8 with more participants in the control group reporting no pain/discomfort (12 vs. 3;  $\chi^2 = 6.01$ ;  $p = 0.01$ ). There were no differences between groups for pain at any of the other time points (Figure 7-12).

Analysis of the EQ-5D sub-categories over time was performed. There were no differences over time for the categories of mobility, pain/discomfort or anxiety/depression. There was a significant decrease in difficulties with usual activities between Week 0 and Week 16 ( $\chi^2 = 20.67$ ;  $p < 0.01$ ) and in difficulties with self-care between Week 0 and Week 16 ( $\chi^2 = 8.31$ ;  $p < 0.05$ ).

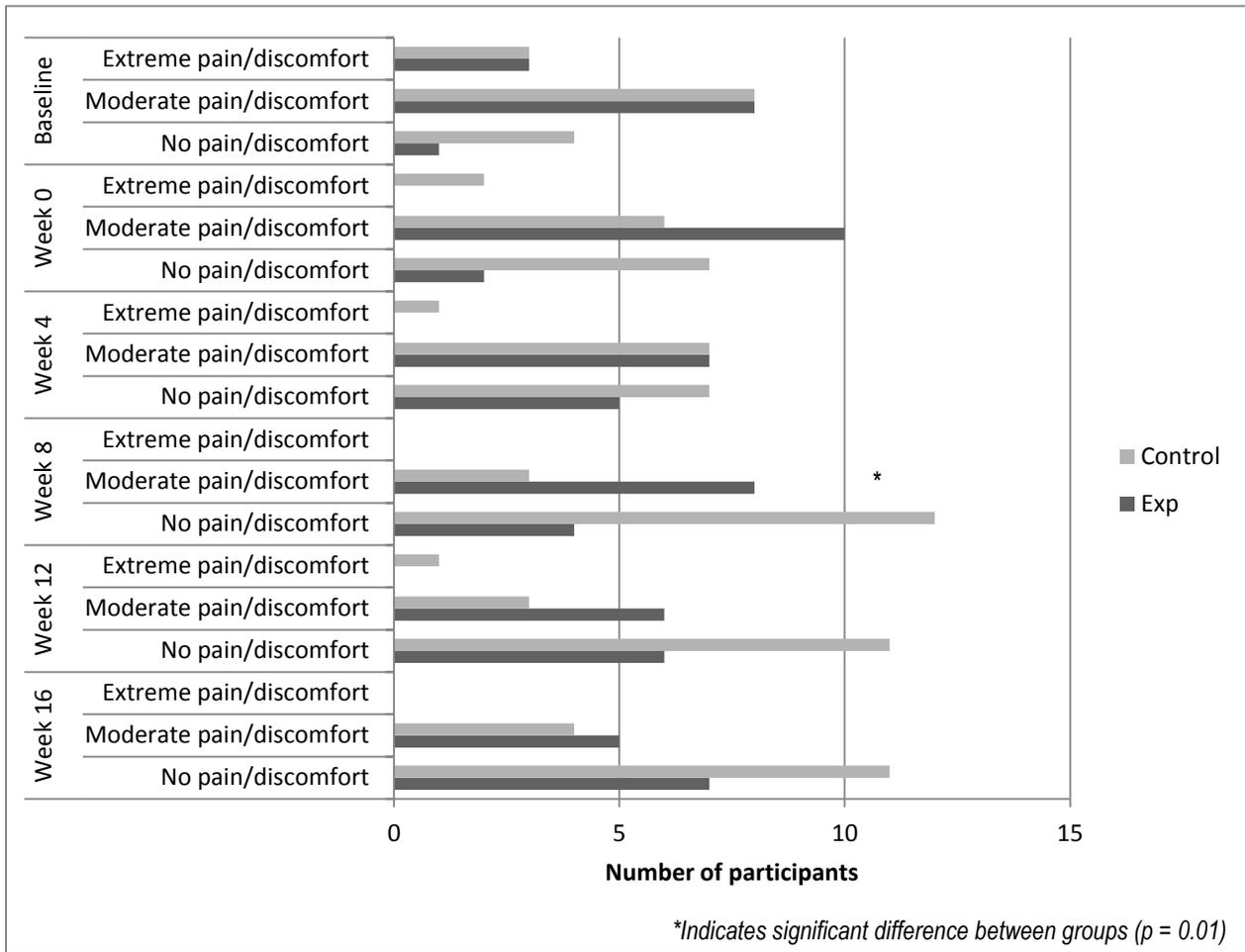


Figure 7-12: Number of participants reporting pain on the EQ-5D (N = 27)

### 7.3.3.5 Beck depression inventory (N = 27)

There were no significant differences between groups in depression scores on the BDI ( $F_{(5-125)} = 0.35$ ;  $p = 0.88$ ) (Table 7-9).

Table 7-9: Scores on the Beck Depression Inventory (N = 27)

	Participants	Experimental Group	Control Group
	Mean ± SD	Mean ± SD	Mean ± SD
<b>Baseline</b>	N = 27	n = 12	n = 15
	19.81 ± 12.29	22.33 ± 13	17.8 ± 11.74
<b>Week 0</b>			
	14.93 ± 9.54	17.83 ± 12.08	12.6 ± 6.43
<b>Week 4</b>			
	11.04 ± 6.88	12.17 ± 7.63	10.13 ± 6.33
<b>Week 8</b>			
	10.26 ± 8.04	12.67 ± 10.16	8.33 ± 5.49
<b>Week 12</b>			
	10.85 ± 9.29	14.58 ± 11.92	7.87 ± 5.21
<b>Week 16</b>			
	8.48 ± 6.68	11 ± 7.92	6.47 ± 4.87

There was a significant difference in depression scores over time ( $F_{(5-125)} = 10.34$ ;  $p < 0.01$ ) (Figure 7-13). There was no improvement in depression scores between Baseline and Week 0. There was a significant improvement in depression scores between Week 0 and Week 16 ( $p < 0.01$ ). Depression scores also improved significantly between Baseline and Weeks 4; 8; 12 and 16 (all  $p < 0.01$ ).

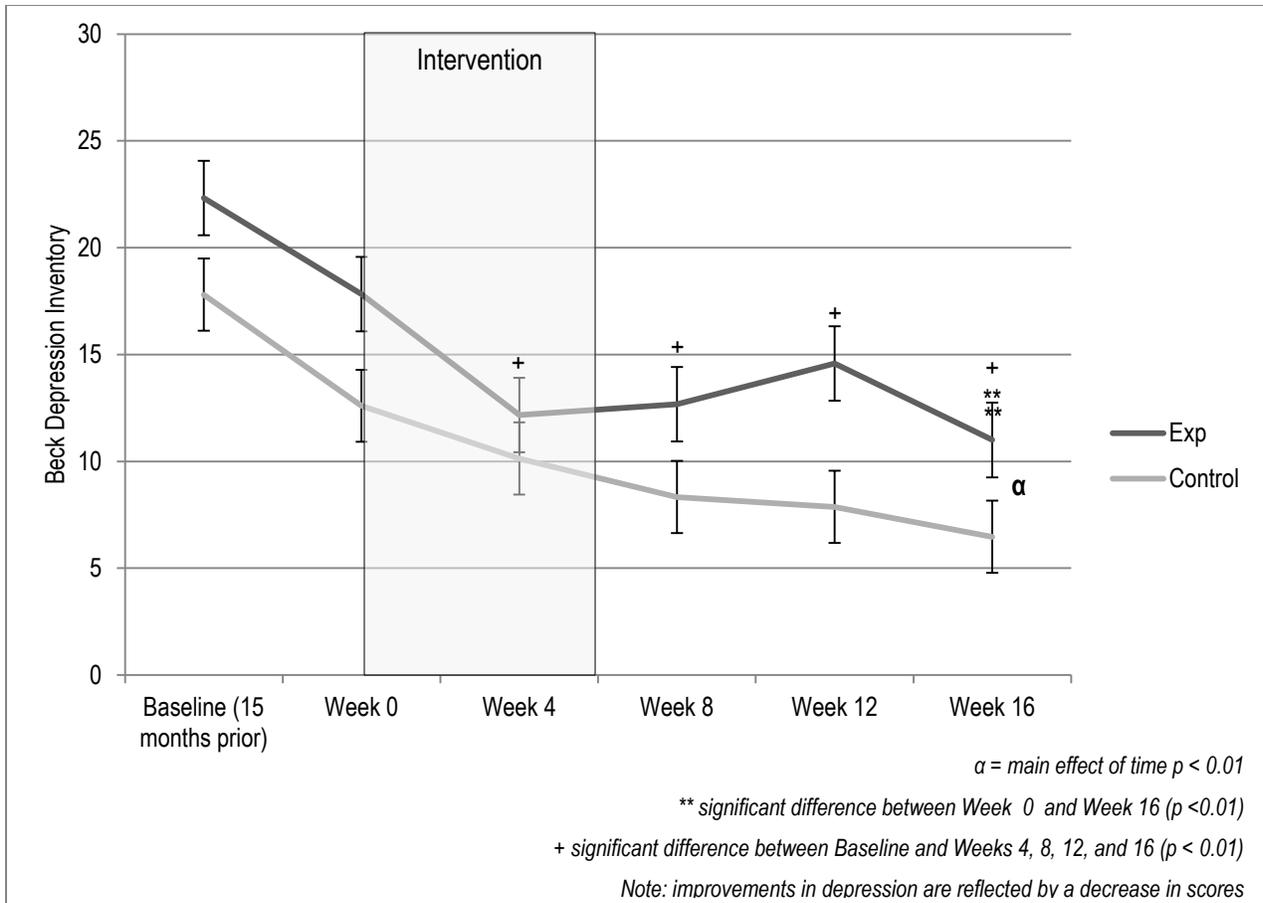


Figure 7-13: Change in scores on the Beck Depression Inventory over time (N = 27)

#### 7.3.3.6 Participants' responses to open ended questioning on the intervention

Participants' responses to three open questions asked at the interviews in Week 16 are presented below.

Participants in the experimental group were asked about the workshops, participants in the control group were asked about the workbook. One negative response was elicited from a participant in the experimental group to the second question asking what they didn't like in the workshops (Participant 30: *"Its people who have gained knowledge in some certain areas but still not open up, people who were not participating in the workshop and people who were not attending. I could not participate also due to some issues."*) From this response, it appears that the participant felt that others in the group were not sharing all of their previous knowledge or that she felt she could not share her own knowledge or experiences due to personal issues (perhaps issues relating to confidentiality). No other negative responses were obtained in response to the questions with participants often reinforcing their answer to the first question or expanding on it in subsequent questions.

Full responses are presented in Appendix L. Responses to the questions were grouped according to themes.

Themes which emerged from participants in both the experimental and control groups on aspects which were liked included, "learning"; "exercise"; and "support". Responses to the first two questions are categorised according to these themes in Table 7-10.

Table 7-10: Responses to the questions “What did you like...”

Theme	Experimental Group (n = 12)	Control Group (n = 15)
	Question: “What did you like about the workshops?”	Question: “What did you like about the workbook?”
<b>Learning</b>	<p>Participant 10: <i>“What I liked about the workshop I learnt a lot.”</i></p> <p>Participant 12: <i>“book was so good in an amazing way It taught me a lot. I read everything,...At least there was a change brought in my life.”</i></p> <p>Participant 13: <i>“I learnt a lot ....”</i> And <i>“What I liked in the course the most is that the knowledge that I did not have about health and HIV AIDS that I am involved in. I have gained so much knowledge. Some things have shaped me so much.”</i></p> <p>Participant 14: <i>“I like it because it taught me many things about HIV status”</i></p> <p>Participant 17: <i>“When I came here I thought it was a waste of...waste of time but I realised no, it is not because some things have helped my life.”</i></p> <p>Participant 18: <i>“What I like is that we were taught those things written in those books.... I liked what we learnt in that book about HIV,... When we started she gave us a book to read and to do homework in it. We were often asked questions in it by .... (peer-leader)”</i></p> <p>Participant 19: <i>“I learnt more”</i></p> <p>Participant 20: <i>“What I liked about the course is that we learnt a lot about things that we did not know and that we must eat healthy, e.g. veg and fruit, water.”</i></p> <p>Participant 26: <i>“This workshop helped me a lot because I have learnt a lot.”</i></p> <p>Participant 30: <i>“What I liked is that it is easier to learn new things and it is easier to learn as a group. I have learnt how to behave and how to deal with problems.”</i></p> <p>Participant 31: <i>“What I liked about this course it taught me a lot.”</i></p> <p>Participant 32: <i>“I have learnt something that I did not know and about my rights.”</i></p> <p>Participant 33: <i>“I liked the workshop because I have gained knowledge that I did not have. So I gained a lot because there were things that were putting me down in life but now I feel encouraged because I was attending. So I gained a lot.”</i></p>	<p>Participant 1: <i>“I have learnt something new I did not know about my life. How to take care of myself”</i></p> <p>Participant 4: <i>“Okay, I am like it, everything there. Ja, because I'm- let's say I'm learning more about my... about my health.”</i></p> <p>Participant 21: <i>“I like the fact that it teaches on how to control my life. Now I can remain in health without any problems.”</i> And <i>“It teaches very well. Everything that I have learnt, it was good. Now I know how to conduct my life because I read that book.”</i></p> <p>Participant 25: <i>“I like the fact that I can teach people because of these books.”</i></p> <p>Participant 32: <i>“I like the way it is designed and the way it teaches us on what to do....”</i></p> <p>Participant 36: <i>“So I have learnt a lot.”</i> And <i>“I even read this book twice.”</i></p>

Theme	Experimental Group (n = 12)	Control Group (n = 15)
	Question: "What did you like about the workshops?"	Question: "What did you like about the workbook?"
<b>Exercise</b>	<p>Participant 14: <i>"The exercise!"</i></p> <p>Participant 10: <i>"now I managed to exercise"</i></p> <p>Participant 17: <i>"Something that I did not like before was exercise because I have never exercised before"</i></p> <p>Participant 18: <i>"I also liked the exercises"</i></p> <p>Participant 20: <i>"...exercising..."</i></p> <p>Participant 31: <i>"Even the exercises that I was not doing; now I am doing them."</i></p>	<p>Participant 1: <i>"I must always try to exercise."</i></p> <p>Participant 11: <i>"I am active as before"</i></p> <p>Participant 22: <i>"I liked it because it shaped me in my weight. I was exercising and it gave me tips on how to exercise. I think that's fine."</i></p> <p>Participant 25: <i>"I can now exercise and so on through those books."</i></p> <p>Participant 29: <i>"Ok, I liked it because it was encouraging me to exercise. I was able to remind myself that I should wake-up and think of exercising."</i></p> <p>Participant 36: <i>"I like the part where it talks about exercises; on how can you exercise..."</i></p>
<b>Support</b>	<p>Participant 10: <i>"Now I can talk to someone when I have a problem, is what I liked about the workshop."</i></p> <p>Participant 13: <i>"...our facilitator, we worked so well with her."</i></p> <p>Participant 30: <i>"And the other thing, I got relieved and I was able to talk with people about my problems." AND "Its people who have gained knowledge in some certain areas but still not open up, people who were not participating in the workshop and people who were not attending. I could not participate also due to some issues."</i></p>	<p>Participant 8: <i>"What I like here is that they ask me about this sickness I have, my positive status and I feel proud about it. Since I started to know my status in 2001 I used to feel very bad when they talk about HIV on radio, but now I have become fine since I have joined support groups and places like these ones. I like to be around the people who are HIV positive like me."</i></p> <p>Participant 9: <i>"What I liked about these books is that the knowledge I have, I share it with my neighbours, sit down with a cup of tea and share the knowledge. Maybe someone is sitting at home stressing and maybe she can't go somewhere else to relive her stress. Maybe if I can invite that person, talk to her maybe the stress can be revealed."</i></p> <p>Participant 11: <i>"It gave me so much interest because now I have back my normal life. Because there are people who care for us who make us do these things so that we can be able to drink our tablets, ARVs. We get to realise that we are not alone, there are people who are supporting us."</i></p>
<b>Sharing</b>		<p>Participant 9: <i>"What I liked about these books is that the knowledge I have, I share it with my neighbours, sit down with a cup of tea and share the knowledge. Maybe someone is sitting at home stressing and maybe she can't go somewhere else to relive her stress. Maybe if I can invite that person, talk to her maybe the stress can be revealed."</i></p>
<b>Knowledge</b>		<p>Participant 25: <i>"I like the fact that I can teach people because of these books."</i></p>

The final question of the interview asked participants to identify aspects they would like to change or add to the workshops or workbook. Participants in the control group who were provided with the workbook only, had no suggestions as to further topics which they would like added to the workbook. The responses of participants in the experimental group, who had attended the workshops, all grouped on the themes of “wishing for the support to continue” and around the idea of wanting others to benefit from the workshop (“sharing the knowledge”). Responses from the experimental group are presented in Table 7-11.

Table 7-11: Experimental group responses to “Would you like to include anything more?”

Theme	Question: “Was there anything more you would like to include in the workshops?”
Sharing the knowledge	<p>Participant 10: <i>“I wish everybody can come to the workshop to learn the way we have learnt. I was scared to talk about it before, but since I came to the workshop I realised that I am not the only one who is sick, there is many of us and we are living a normal life.”</i></p> <p>Participant 13: <i>“I wish that more people could join in this course”</i></p> <p>Participant 19: <i>“I wish you could continue with it up to our children. I do not know what could happen if you cannot do this course, because it can be very helpful even to our children and show them it is not the end of life.”</i></p> <p>Participant 30: <i>“I was thinking that people should bring their partners or people who are going to support them in this program. It is so much helpful, so that in what we learn we can share and not keep this knowledge to ourselves. Coming as groups was a right thing. I hope what we are learning it does not end here, so that even other people can get help.”</i></p>
Wishing for support to continue	<p>Participant 26: <i>“I would like it to continue. I am thinking if we can continue to sit down and talk about these things we can learn a lot.”</i></p>

### 7.3.3.7 Summary of results

Twenty-seven women participated in the study to compare the effects on pain of participating in a six-week peer-led exercise and education intervention with provision of a workbook. With regard to socio-economic and demographic characteristics there were no differences between the experimental group (n = 12; attending the peer-led intervention) and the control group (n = 15; received the workbook only) in age, the number of languages participants were able to write or speak, employment status, educational level or marital status. There was no difference between groups in current smoking or alcohol consumption. However, six participants in the control group had previously smoked compared with none in the experimental group ( $\chi^2= 6.17$ ;  $p = 0.01$ ).

HIV/AIDS stage, clinical presentation and management of the participants at recruitment into the intervention study (Week 0) revealed minor differences between the groups. There were no differences between groups in stage of disease, CD4+ count or treatment.

Two of the participants in the experimental group were on d4T at Week 0. In the control group, only one participant was on d4T at Week 0. There was no statistical difference between groups.

Comparison of the Week 0 measures with the measures obtained in the survey conducted 15 months previously (a period of normal care with no interventions), showed no significant changes in disease parameters, prevalence of pain, pain severity (PSS), pain interference (PIS), self-efficacy, EQ VAS or depression. There was a significant improvement in the EQ-5D index ( $p = 0.01$ ) between Baseline ( $0.61 \pm 0.34$ ) and Week 0 ( $0.76 \pm 0.22$ ).

There was no difference between the experimental and control groups at any of the time points in any of the measures. There was a significant reduction in the prevalence of pain between Week 0 and Week 4 ( $\chi^2 = 4.59$ ;  $p = 0.03$ ) and a continued reduction in pain prevalence to Week 16. For PSS and PIS, there was a significant effect of time with participants' having improvements in PSS ( $p < 0.01$ ) and PIS ( $p < 0.01$ ) at Weeks 4, 8, 12 and 16. Compared with Week 0, there were improvements in self-efficacy at Week 16 ( $p = 0.03$ ), HRQoL EQ-5D index at Week 8 ( $p = 0.03$ ) and Week 16 ( $p < 0.01$ ) and depression at Week 16 ( $p = 0.04$ ). There were no changes in disease parameters over the 16 weeks of the study.

#### 7.3.4 Discussion

The aim of this study was to assess the effects of a six-week peer-led exercise and education intervention on pain in amaXhosa women living with HIV/AIDS. The main findings of the study were that there was a significant decrease in the primary outcome variable of pain severity and in the secondary variables of pain prevalence and pain interference in all participants over the 16 weeks of the study. Notably there was no change in pain during the 15 months prior to the study when participants were receiving normal care. The intervention programme and workbook both appeared acceptable to the participants, feasible to deliver and participant responses were positive in relation to both the education component of the programme and exercise. Several participants commented on the fact that they had not been exercising previously but through the intervention and workbook they were now enjoying the benefits of exercise.

This discussion will initially review the recruitment and size of the sample. The socio-economic, demographic and clinical characteristics of the participants will then be discussed prior to discussion on the effect of the intervention on pain severity, interference and management, and on SE, HRQoL and depression. Finally the participants' feedback on the intervention and workbook will be discussed prior to presentation of the clinical implications and study limitations.

#### 7.3.4.1 Sample

Telephone calls were made to all 170 women reporting pain in the study reported on in Chapter 6. Many of the women could not be contacted, a reflection of the itinerant nature of the informal settlement where the study was conducted. This is a problem other studies conducted in this community have encountered<sup>85 228</sup>. Difficulty with follow-ups is a common feature of studies conducted in similar communities across South Africa and although wide use of cellular telephones has assisted with this (in the present study where participants had moved out of the area of the study at follow-up, interviews were conducted telephonically), the challenge remains both in research and in the delivery of health care in chronic diseases<sup>327</sup>. In future studies, it may be helpful to request participants to provide a secondary address and telephone number in order to increase the rate of follow-up.

The women participating in this study had similar socio-economic and demographic characteristics to those who participated in the study described in Chapter 6 with similar education and employment profiles, marital status and age as those who took part in the larger survey and similar to the majority of female residents of the area<sup>265</sup>. Comparison of the experimental and control groups revealed no differences between the groups in any of these variables.

There were significant differences between groups in terms of previous smoking history with more members of the control group reporting that they had smoked in the past. This may have affected outcome as levels of SE in people who have successfully ceased smoking is recognised to be higher than those who have either not tried to change or have not succeeded in making a change<sup>328</sup>. Thus the control group may have been primed to succeed in an intervention aimed at behaviour change.

#### 7.3.4.2 Disease parameters

The sample had a similar disease profile to the participants in Chapter 6 (Section 6.4.1, p.128). In addition there were no differences in disease parameters between the groups. However, more participants in the experimental group had been treated with d4T or were still receiving d4T at Week 0. Although this was not a significant difference it may have influenced responses to the intervention as d4T is associated with painful peripheral neuropathies<sup>43 119</sup>. In addition, one member of the experimental group had been diagnosed with pulmonary Tb and although she had initiated treatment this opportunistic infection may have affected her response to the intervention. While the differences were not significant, overall, the experimental group appeared to have more severe illness than the control group with more participants on second line ART, lower CD4+ counts and more opportunistic infections. This may have had an influence on the experimental group's ability to respond to an intervention.

#### 7.3.4.3 Effects of normal care

There were no significant improvements in PSS and PIS over the 15 month period of normal care between the baseline measures being obtained for the study reported on in Chapter 6 and the beginning of the intervention for the participants in either the experimental or control groups (Section 6.4.2, p.135). The 15 month period is effectively a waiting list control for all the participants. Similarly there were no changes in SE, or depression. These data indicate that despite receiving ART and attending the CHC for regular monitoring of their condition, they continued to suffer with pain.

#### 7.3.4.4 Effects of the intervention

There were no differences between the experimental and control groups over the 16 week study period in any of the variables. However, there was a main effect of time for all variables indicating that participating in the study had a positive effect. Prevalence of pain decreased markedly across the cohort over the 16 weeks of the intervention study. Over the 16 weeks of the study, the prevalence of pain fell 73%, i.e. while all 27 participants had pain at Week 0; this had decreased to only seven participants reporting pain at Week 16. Participating in the study, whether as a member of the control or the experimental groups appeared to be beneficial.

The change in pain prevalence scores are reinforced by the changes in PSS and PIS scores. The lack of difference between groups in these scores over the 16 week intervention study period suggests that either the workbook alone was sufficient to impact on pain, or simply participating in a study reduced pain when compared with normal care.

The phenomenon of participants responding positively when taking part in a study is not a new one and is frequently referred to as the Hawthorne effect<sup>329 330</sup>. However, the original theory of the Hawthorne effect has been criticised as overly simplifying the impact of psychosocial factors on human functioning, both of the caregiver and of the patient in health care studies<sup>330</sup>. Initially, it was theorised that patients performed better when taking part in studies because of the perceived greater care and attention they received, essentially a placebo effect. However, it is now clear that health care practitioners and researchers also change their behaviour and adjust their communication strategies when conducting research with patients. The change in behaviour results in patients feeling more “cared for”; not simply due to participating, but due to the increased attention and care they are receiving from health professionals involved in the study<sup>331</sup>. The placebo effect in such a setting is not therefore a nonspecific by-product of the interaction but rather has been purposively generated through a caring therapeutic relationship<sup>332</sup>. This “care factor” may stimulate a powerful analgesic placebo response as a consequence of a release of endogenous opioids with a positive impact on pain<sup>333</sup>.

The significant early improvements in pain in all the participants are noteworthy as changes in pain measures following participation in chronic pain management programmes often occur secondary to improvements in function and SE<sup>204</sup>. However, although the improvements are statistically significant, it was only at Weeks 12 and 16 where the improvements in PSS and PIS neared three points out of a possible 10, the minimum change required for patients to report feeling better<sup>129 217</sup>. Despite this, the time to clinically relevant and significant improvements in pain was relatively short. In chronic pain management programmes improvements in pain may only occur six to twelve months later and even at this time point may not be clinically relevant<sup>295 334</sup>. Rather than pain changing subsequent to changes in SE, depression and HRQoL, pain in this group appeared to change first. It is proposed that participants in the study initially responded positively to the therapeutic relationship, the “care factor”. This “care factor” may have resulted in small but significant improvements in pain initially; followed by an improvement in HRQoL, leading to a change in SE with a consequent change in behaviour leading to further improvements in pain.

The model of health care used in community health ART clinics means that patients may see different health care professionals at each visit. The therapeutic relationship is hindered in this system and the environment may be viewed as hostile. The hostility of the health care system has been noted to negatively impact on care seeking behaviours, drug adherence and outcomes<sup>335 336</sup>. This hostility may be a product of the structure of the system or a product of behaviours of health care providers such as the perceived friendliness or unfriendliness of staff<sup>336 337</sup>. Some authors would regard this hostility as having a placebo effect as no therapeutic relationship can be built upon<sup>332</sup>. If the improvement observed in both groups in the present study is a consequence of the “care factor” i.e. seeing the same researcher, who is regarded as friendly, on a regular basis which has allowed for a therapeutic relationship to develop, modifications to the model of service delivery used in the clinics with named clinicians may be the most effective treatment available.

Similar to the changes in PSS and PIS, there were no differences between groups in the PMI; however, there was a main effect of time. While there was no change in the PMI during the 15 months of normal care, there was a significant improvement during the intervention study. However, this change was only significant at Weeks 12 and 16, after the improvements in PSS and PIS. As the PMI is calculated from the PSS, this improvement is not surprising although it is concerning that despite the improvements in pain; the PMI remained below zero, indicating that the participants with pain were still being undermanaged pharmacologically.

Despite patient and physician barriers to effective pain management having previously been identified<sup>43 338</sup>, a pattern of under-management has been highlighted in several studies<sup>6 7 79 128</sup>. This result suggests that in spite of addressing previously recognised patient barriers to effective pain management in the workbook, this may not have been adequate and the sections covering pharmacological management of pain and communicating with health care professionals should be reviewed. In addition, further research exploring barriers to pain management in South African contexts may identify different or additional barriers not previously described.

No previous studies were found which focussed on the effect of an intervention on pain in PLWHA. Previous studies exploring the effect of a similar intervention on self-management in PLWHA have reported conflicting results<sup>2 127 282</sup>. The first trial of a peer-led education programme for homosexual males living with HIV/AIDS reported positive results for symptom severity, but not for pain, fatigue or psychological symptoms<sup>2 127</sup>. However, a follow up study using the same method with female former IDUs living with HIV/AIDS reported no differences between the experimental and control groups in symptom severity<sup>282</sup>. The author of the second study proposed that there was a decreased response due to an increase in knowledge generally in PLWHA with the sample having a longer time since diagnosis than those in the initial study by Gifford et al<sup>127</sup>. The authors of both studies suggest that when working with groups with relatively high levels of education regarding their condition there may well be a “ceiling effect” limiting the impact of the intervention. The results of the present study may be a reflection of the impact of any education on living with a chronic disease in a population where appropriate disease specific educational resources are scarce and levels of education are low. The effects of the intervention on the variables of self-efficacy, HRQoL and depression will now be discussed.

#### *Self-efficacy*

There were no differences between groups in improvement in SE. However, as with pain, there was a main effect of time at Week 16 compared to Week 0 ( $p < 0.01$ ). The limited improvement in SE was unexpected as the workbook was developed based on social behaviour theory with the inclusion of specific tasks aimed at increasing SE. This result is in direct contrast to the positive effects on SE of other similar interventions designed for PLWHA<sup>2 127 282</sup>.

It may be that the women participating in this study had high levels of SE prior to enrolment as the SE scores changed marginally on the ten point scale. It has previously been noted that PLWHA in sub-Saharan Africa have better adherence rates than in higher income countries<sup>339</sup>. It could be suggested that this is a reflection of higher levels of SE and of the limited number of IDUs in this population.

As mentioned earlier, it is noteworthy that the change in SE was only significant at Week 16, a considerable period of time after the improvements in pain were first observed at Week 8. Self-efficacy has been identified as a mediator to reduce pain in chronic musculoskeletal conditions<sup>204</sup>. However, in this group of women, self-efficacy did not appear to impact on pain.

Considering the results presented in Chapter 6 where there was no relationship between SE scores and PSS or PIS this is perhaps not surprising. However, the role of SE should not be dismissed outright as the instrument used in this study to measure SE has had limited use in this population group and its validity has not been fully established. Hence the lack of change in SE may simply be a reflection of an instrument with poor responsiveness.

#### *HRQoL*

There were no differences between groups in improvement in EQ VAS or for the EQ-5D index. There were also no significant improvements in EQ VAS between Week 0 and Week 16 suggesting that the intervention had no impact on participants' self-reported state of health. However, there were significant improvements in the EQ-5D index between Week 0 and Week 8 indicating that the state of health VAS may have been less sensitive to change over time. When analysed by sub-category there were only significant changes over time in the category for pain. Considering the contributing role of difficulties in mobility and difficulties in usual care to the prevalence of pain identified in Chapter 5, it is surprising that changes in these factors are not apparent. Similar to the SE scores, the improvements only occurred after the significant changes in pain. Considering the moderate correlation between pain and the EQ VAS identified in Chapter 5, pain may be the driving factor behind the change in HRQoL rather than HRQoL influencing pain.

#### *Depression*

There were no differences between groups in improvement in depression scores. However, as with pain, there was a main effect of time at Week 16 compared to Week 0 ( $p < 0.01$ ). Scores on the BDI dropped to below 13 at Week 8 indicating minimal depression<sup>179</sup>. Previous studies have reported that participants with moderate to severe depressive symptoms are less likely to respond to education interventions<sup>2</sup>. However, moderate levels of depression, as measured by the BDI, did not appear to impair response in this sample. It may be that the use of exercise in combination with the education intervention ameliorated the impact of depression on participants as exercise is known to be beneficial for the symptoms of depression, particularly in mild depression<sup>340</sup>. Thus it may be that the inclusion of exercise in the programme had short term beneficial effects allowing participants to engage with the education component.

The three variables of SE, HRQoL and depression all improved over time in the study participants. However, the improvements were only significant after the significant improvements in pain were recorded. It seems that, as with other chronic conditions, there are complex interrelationships between pain and other variables. Considering the biopsychosocial model of pain, this is not unexpected and perhaps the overall message should be that rather than searching for a single "magic bullet" to address the multiple aspects of suffering experienced by these patients, health care should focus on working with the embodied patient using a wide range of treatment tools and approaches.

The final aim of this study was to evaluate the acceptability of the intervention and the workbook. The responses of participants to three guided interview questions will now be discussed.

#### 7.3.4.5 Interviews

Both the intervention and the workbook appeared to be acceptable to the participants. Responses were positive to all questions with participants most frequently emphasising the learning component of the intervention. Previous studies have emphasised the benefits of learning in patients with chronic conditions<sup>127 209</sup>. Despite living with HIV for an extended period of time, the participants still had health education gaps which they felt were addressed in the workbook or the intervention. In particular, one participant reported that she didn't think she had anything more to learn and yet had acquired new knowledge. In addition, unlike a previous study where peer-leaders and participants had low levels of education<sup>282</sup>, none of the participants indicated that the literacy level of the workbook or of the intervention was too high with no identification of difficulty understanding the content. Nor was there any indication that the information provided was redundant.

The second most commonly reported positive aspect was "exercise". Participants in the experimental group reported enjoying the exercises and being able to do them. It was surprising that participants in the control group also reported that they were encouraged to exercise after reading the workbook and reported activity levels increasing or returning to previous levels. A factor which contributes to exercise uptake and adherence is an understanding of the benefits of participating<sup>341</sup>. The workbook may have sufficiently motivated participants regarding the importance and benefits of exercise both through content and positioning of the topic of exercise in the first week. This is an encouraging response when the multiple benefits of exercise, such as its impact on symptom management, prevention of chronic diseases of lifestyle, and addressing depressed mood are considered. The positive response to exercise in this intervention emphasises the role of physiotherapy in assessing, screening and prescribing exercise in PLWHA.

Participants in both the experimental and control groups identified "support" as a positive benefit of the intervention. This was somewhat surprising for the control group as they were not offered any group environment. However, it appears that these participants used the workbook to facilitate the creation of their own community based support groups (Participant 9, Table 7-10, p. 201). Both these positive aspects ("exercise" and "support") may have been facilitated by the use of group work. One of the theorised benefits of groups is to facilitate participation in activities such as exercise with home exercise programmes often reported as being less effective than supervised exercises<sup>341 342</sup>. Working in a group enhances learning through personal experience (sharing of goals and having accountability), and vicarious experience<sup>315</sup>. The formation of groups appeared to have been effective in creating supportive environments. Finally the participants indicated a wish that the intervention could be continued and offered to others. This reinforces the initial positive feedback suggesting that the benefit which they felt they gained would be beneficial for others too.

#### 7.3.4.6 Study limitations

The Consolidated Standards for Reporting Trials (CONSORT) guidelines were used as a benchmark for evaluating study limitations<sup>343</sup>. The guideline criteria are presented in Table 7-12 with indication of how these were addressed in the study.

There were three main limitations to the study relating to the sample, and study design. It must be noted that the participants in this study were all amaXhosa women living in a resource poor community. This implies that these results may not be presumed to be transferrable to other social groups and separate studies should be conducted to explore the efficacy and acceptability of the intervention in groups of men and in different cultures.

Further limitations relate to the study design. The participants in the study were followed up for a 16 week period. In terms of achieving long term behaviour change for the management of chronic disease this is a short time period. Studies on the effect of educational interventions for chronic disease have shown that behaviour change may initially be achieved but follow up over a minimum period of one year is recommended to monitor for prolonged effects<sup>282 312</sup>.

Finally, the use of a control group who were provided with the same workbook as that used in the intervention has limited interpretation of the results. While the design of providing the control group with material has been used in previous studies<sup>282</sup>, and can be justified from an ethical standpoint, it means that it is not possible to discern whether the control group improved as a consequence of the workbook or due to participating in the study. This is a fundamental question which needs to be explored. As mentioned earlier, the “care factor” of participating in a study and seeing the same person in a clinical setting on a regular basis may explain the improvement observed in both groups and is worthy of further research.

Table 7-12: CONSORT guidelines and indication of section where items were addressed

Section/Topic	Item No	Checklist item	Reported in
<b>Title and abstract</b>	1b	Identification as a randomised trial in the title	Abstract
		Structured summary of trial design, methods, results, and conclusions	Will be specified for publication
<b>Introduction</b>	2a	Scientific background and explanation of rationale	Section 7.1 and
Background/objectives	2b	Specific objectives or hypotheses	Section 7.3.1
<b>Methods</b>			
Trial design	3a	Description of trial design (such as parallel, factorial) including allocation ratio	Section 7.3.2.1
	3b	Important changes to methods after trial commencement (such as eligibility criteria), with reasons	
Participants	4a	Eligibility criteria for participants	Section 7.3.2.2
	4b	Settings and locations where the data were collected	Section 7.3.2.3
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	Section 7.3.2.5
Outcomes	6a	Completely defined pre-specified primary and secondary outcome measures, including how and when they were assessed	Section 7.3.2.8
	6b	Any changes to trial outcomes after the trial commenced, with reasons	
Sample size	7a	How sample size was determined	Section 7.3.2.2
	7b	When applicable, explanation of any interim analyses and stopping guidelines	
Randomisation:	8a	Method used to generate the random allocation sequence	Section 7.3.2.6
Sequence generation	8b	Type of randomisation; details of any restriction (such as blocking and block size)	
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	Section 7.3.2.6
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	Section 7.3.2.6
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	Section 7.3.2.6
	11b	If relevant, description of the similarity of interventions	

Section/Topic	Item No	Checklist item	Reported in
Statistical methods	12a	Statistical methods used to compare groups for primary and secondary outcomes	Section 7.3.2.8
	12b	Methods for additional analyses, such as subgroup analyses and adjusted analyses	
<b>Results</b>			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were randomly assigned, received intended treatment, and were analysed for the primary outcome	Figure 7-3
	13b	For each group, losses and exclusions after randomisation, together with reasons	
Recruitment	14a	Dates defining the periods of recruitment and follow-up	Section 7.3.3.1
	14b	Why the trial ended or was stopped	
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	Table 7-2 – 7-5
Numbers analysed	16	For each group, number of participants (denominator) included in each analysis and whether the analysis was by original assigned groups	Section 7.3.3
Outcomes and estimation	17a	For each primary and secondary outcome, results for each group, and the estimated effect size and its precision (such as 95% confidence interval)	Section 7.3.3
	17b	For binary outcomes, presentation of both absolute and relative effect sizes is recommended	
Ancillary analyses	18	Results of any other analyses performed, including subgroup analyses and adjusted analyses, distinguishing pre-specified from exploratory	Section 7.3.3.6
Harms	19	All important harms or unintended effects in each group	
<b>Discussion</b>			
Limitations	20	Trial limitations, addressing sources of potential bias, imprecision, and, if relevant, multiplicity of analyses	Section 7.3.4.6
Generalizability	21	Generalizability (external validity, applicability) of the trial findings	Section 7.3.4
Interpretation	22	Interpretation consistent with results, balancing benefits and harms, and considering other relevant evidence	Section 7.3.4
<b>Other information</b>			
Registration	23	Registration number and name of trial registry	N/A
Protocol	24	Where the full trial protocol can be accessed, if available	N/A
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	Acknowledgements

## 7.4 Conclusion

The aim of this study was to develop and test an intervention programme designed to assist with the management of pain in amaXhosa women living with HIV/AIDS. A six-week peer-led exercise and education intervention was developed for use with amaXhosa women living with HIV/AIDS. There was no difference between the experimental and control groups but there was a large effect of time with improvements in all variables in both groups. Specifically, the workbook developed for the intervention and the intervention itself resulted in significant improvements in pain severity, pain interference and pain management compared to normal care. In addition there were improvements in self-efficacy; health related quality of life on the EQ-5D index and depression over time

Reflection on the interview responses of the participants reveals parallel stories. Participants in both groups were able to use the knowledge provided through the workbook. This was not an expected outcome. It appears that amaXhosa women living with HIV/AIDS need tools to cope with the chronic condition and, despite living in low income communities, are able to effectively utilise knowledge provided.

### 7.4.1 *Clinical implications*

The six-week peer-led exercise and education intervention using the “Positive Living” workbook appears to be an acceptable, feasible and efficacious method to treat pain in amaXhosa women living with HIV/AIDS. Although further work is required to fully understand the mechanism of the effect, the efficacy and acceptability of the programme coupled with the low resource requirements for running the intervention (peer-led and group format) increase its applicability in a primary healthcare setting. Considering the apparent acceptability and effectiveness of the workbook and intervention in the women participating in this study, it is worth exploring the clinical applicability of this intervention. In particular, the use of the workbook alone may be sufficient to improve pain and other variables in amaXhosa women living with HIV/AIDS.

### 7.4.2 *Research implications*

A further study is indicated. The study would need to have a larger sample size with longer follow-up periods to allow for further analysis. In addition, a three arm design is proposed with a control group receiving no intervention other than regular interview appointments, and two experimental groups as were used in the present study. This would allow the researchers to explore whether the responses of the control group in the present study were as a consequence of being provided with the workbook or were a result of developing a therapeutic relationship with the research assistant who conducted the data collection interviews.

## Chapter 8: Conclusion

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With the introduction of ART, PLWHA have a greater life expectancy. However, the quality of the years gained may be severely compromised if the person living with HIV/AIDS continues to suffer from symptoms such as pain. While the HIV/AIDS pandemic initially required health care to focus on preventing death from the virus and the complications of infection, the introduction of effective medication has resulted in a shift to a chronic disease management model with an emphasis on enhancing quality of life<sup>3</sup>. Recognising the prevalence and under-management of pain in PLWHA, the aim of this thesis was to determine the characteristics, contributing factors and management of pain in PLWHA with particular reference to amaXhosa women living with HIV/AIDS.

### 8.1 Pain in HIV/AIDS

In this thesis, the ICF was used as a theoretical framework to explore pain within a biopsychosocial model. This model proposes that pain is a consequence of and is influenced by multiple interactions between numerous variables. Variables which may originate from biological, psychological or social mechanisms and events<sup>344</sup>. Based on the data presented in this thesis, the pain experienced by PLWHA is patently biopsychosocial. Although the high prevalence of pain in PLWHA reported on in both the systematic review (Chapter 3) and the study on amaXhosa women living with HIV/AIDS (Chapter 6) could be interpreted as reflecting a symptom of biological origin common to all PLWHA, the diversity of pain recorded and the interactions and influence of psychosocial factors suggest another interpretation.

Pain of predominantly biological origin may be expected to follow a clear trajectory, have distinct features and would be expected to respond to pharmacological management in a predictable manner. Pain of biopsychosocial origin may well have biological contributors but these interact with diverse psychosocial variables such as levels of education, depression and SE which impact on the severity and impact of the pain. In addition, pain of biopsychosocial origin may equally stem from psychosocial factors and be compounded by biological factors. The characteristics and contributing factors to pain in PLWHA described in this thesis support the model of pain in PLWHA as biopsychosocial in nature.

The biopsychosocial nature of pain in HIV/AIDS is further supported by the results of the intervention study presented in Chapter 7. During the 15 month period of normal care when the participants in the intervention study were receiving routine pharmacological management of their HIV/AIDS condition, there was no improvement in pain. However, the intervention programme, either through the workbooks or via the peer-led groups and the workbook, addressed both biological factors (through exercise) and psychosocial factors (through exercise, education and SE among others) with significant effects on pain.

The decrease in pain prevalence, pain severity and pain interference all strengthen the proposition that pain in PLWHA has biopsychosocial mechanisms and will respond to treatment based on this model. It is the author's opinion that pain in PLWHA is not purely a consequence of disease processes but rather that pain is a reflection of a human being's suffering with a debilitating lifelong disease within a societal context which is at times harsh and unforgiving.

The research presented in this thesis aimed to answer a series of objectives based on the aim of determining the characteristics, contributing factors and management of pain in PLWHA with particular reference to amaXhosa women living with HIV/AIDS. The findings are summarised below according to the specific research objectives stated in Chapter 1 (p. 4).

### 8.1.1 Chapter 3: Pain in people living with HIV/AIDS; a systematic review

The first two objectives of Chapter 3 were to determine the *prevalence and characteristics of pain in PLWHA* based on the available literature. Further objectives were to explore the *factors contributing to pain, pain management and the functional impact of pain in PLWHA*. A systematic review of the literature on HIV/AIDS, quality of life and pain was conducted.

Pooling of the data in the systematic review produced a prevalence of pain ranging from a point prevalence of 54.9% (95%CI 51.14 – 56.09), to 55% over one-week (95%CI 57.71 – 62.84), 62% over two-weeks (95%CI 54.59 – 61.25), and 67% over a one month recall period (95%CI 65.9 – 69.24). The pain recorded in the studies reviewed was of moderate to severe intensity (a score of > 5 out of 10) i.e. pain of sufficient severity to have a significant impact on ability to function and quality of life. When present, pain in PLWHA was present at more than one anatomical site with the most commonly reported sites of pain being the lower limbs and head pain. Notably, the prevalence of pain has not diminished over the 30 years spanning the review.

Common factors identified as contributing to pain in the studies reviewed included a history of IDU, being female and of African-American descent. In addition, several studies reported that depression, anxiety and a lack of social support increased risk of pain as did lower levels of education.

Under-treatment of pain was reported in several studies with the majority of PLWHA receiving no pharmacological treatment for pain. In addition, no improvement in pain management indices in more recently conducted studies was noted. The pain affecting PLWHA was reported to have functional effects with consequences for health related quality of life.

Chapter 3 concludes that pain continues to be a problem for PLWHA despite the rollout of ART with between 55% and 67% of PLWHA reporting pain with a high proportion having marked under-treatment of pain. The review identified a variety of factors which contribute to pain including biological, psychological and social factors. These imply that the biopsychosocial model is a useful paradigm for clinicians and researchers to use in addressing not only nociceptive (biological) contributors to pain but also psychosocial factors such as depression and anxiety. The scale of the problem, the under representation of populations from low-income countries and, in particular, of females in the studies reviewed, indicated the need for further work in these groups with careful consideration of ethnicity and cultural factors.

### 8.1.2 Chapter 4: Instrumentation – selection and translation

The next specific objectives of this thesis were to *identify appropriate measurement instruments to explore pain and its contributing factors in amaXhosa women living with HIV/AIDS* and to *translate instruments into isiXhosa* if Xhosa versions were not available. Based on the systematic review instruments were sought to obtain measures of pain (including prevalence, pain severity, pain interference, sites of pain and pain management) in addition to instruments to explore factors which may contribute to pain such as self-efficacy, HRQoL, trauma and depression. Psychometrically sound measurement instruments were identified, namely the:

1. Brief Pain Inventory (BPI)
2. Self-efficacy for managing chronic disease 6-item scale (SE-6)
3. EQ-5D health related quality of life instrument
4. Beck depression inventory (BDI)
5. Childhood trauma questionnaire (CTQ)
6. Harvard trauma scale for PTSD (HTS)

However, valid isiXhosa versions of three of the instruments (BPI, SE-6 and CTQ) could not be identified. Content, semantic and technical equivalence of the BPI-Xhosa, SE-6-Xhosa and the CTQ-Xhosa instruments was ensured using a rigorous forward-translation, back-translation process with a committee approach. Specific issues of cultural relevance and acceptability of the instruments as well as technical issues to ensure culturally acceptable administration of the instruments were explored. Testing of the newly translated instruments in a small group of amaXhosa women suggested that the instruments were acceptable, had semantic equivalence and had technical utility.

### 8.1.3 Chapter 5: Instrumentation – validity and reliability

In this chapter, the third objective of the thesis of establishing *valid and reliable measurement instruments for use in amaXhosa women living with HIV/AIDS* was addressed. The validity and reliability of the newly translated instruments (BPI-Xhosa, CTQ-Xhosa, SE-6-Xhosa) was determined and the test-retest reliability of all the instrumentation used in the study was explored (BPI-Xhosa, SE-6-Xhosa, CTQ-Xhosa, EQ-5D-Xhosa, BDI-Xhosa, HTS-Xhosa).

Two of the newly translated instruments, BPI-Xhosa and the SE-6-Xhosa, were found to have similar psychometric properties to the original instruments. Although the CTQ-Xhosa did not retain the same psychometric properties as the original instrument, it exhibited similar properties to the validated Swedish version. The BPI-Xhosa and the SE-6-Xhosa had good concurrent validity when compared with the previously validated HRQoL instrument, the EQ5D-Xhosa. Further, all three instruments had acceptable reliability with alpha values of  $> 0.7$  on calculations of internal consistency. Finally, all six of the instruments (BPI-Xhosa, CTQ-Xhosa, SE-6-Xhosa, EQ5D-Xhosa, BDI-Xhosa, HTQ-Xhosa) had good to excellent intra-observer reliability.

Based on this data, an appropriate set of measurement instruments which would inform on the prevalence, characteristics and biopsychosocial contributors to pain in amaXhosa women living with HIV/AIDS was established.

### 8.1.4 Chapter 6: Pain in amaXhosa women living with HIV/AIDS

The objective of the research presented in this chapter was to establish *the prevalence, characteristics and contributing factors to pain in amaXhosa women living with HIV/AIDS*. The measurement instruments identified, translated and validated in Chapter 4 and Chapter 5 were utilised, informed by the review of the causes of pain in PLWHA presented in Chapter 2, the findings of the systematic review of Chapter 3 and based on the biopsychosocial model presented in Chapter 1.

In this study, 229 women were interviewed and asked if they had experienced pain (“other than every day kinds of pain”) in the last week. Of these, 170 reported pain, a prevalence of 74.24% (95%CI 68.2 – 79.47%); a rate markedly higher than reported elsewhere despite all participants being ambulatory outpatients (Chapter 3). The PSS and PIS of this sample were in the moderate range (scores  $> 5$ ) indicating pain of sufficient intensity to interfere with various functions such as cognition, activities, sleep and social interactions. In addition, the women had marked under-treatment of pain with only two of the 170 women with pain receiving adequate pharmacological therapy for their pain according to the pain management index.

The women with pain had worse scores than those without pain in a wide range of demographic and psychosocial variables but not in any disease variables. In particular, those with pain were worse off in terms of levels of education, SE, HRQoL (in particular relating to usual activities and mobility), depression and PTSD.

This study emphasizes the prevalence of pain in this population and the need to prioritise pain assessment and management in amaXhosa women living with HIV/AIDS. In addition, recognition of the role of psychosocial variables as contributors to pain highlights the possible role for non-pharmacological management approaches.

### *8.1.5 Chapter 7: The effects of a six-week peer-led exercise and education intervention on pain in amaXhosa women living with HIV/AIDS*

The final objectives of this thesis were to *develop and test an intervention programme aimed at managing pain in amaXhosa women living with HIV/AIDS and reporting pain*. A six-week peer-led exercise and education intervention based on the biopsychosocial chronic disease management model was developed for use with amaXhosa women living with HIV/AIDS. The intervention programme was a peer-led exercise and education programme which included a workbook covering several topics and integrating problem solving and goal setting exercises (Appendix G). The control group were only provided with the workbook developed for the intervention and received no further input.

The peer-led intervention was tested in a single-blind randomised controlled trial with a 16 week follow up period. Both the experimental and the control groups had significant improvements in pain severity, pain interference and pain management compared to normal care. In addition there were improvements in self-efficacy; health related quality of life on the EQ-5D index and depression.

Qualitative feedback on both the intervention and the workbook indicate that these are acceptable in, and liked by the target population. Both the workbook and the intervention programme appeared to make clinically significant differences to the pain and suffering of these women. The study was of sufficient power for the motivation of the clinical roll-out of this intervention or workbook in this group of women.

## 8.2 Recommendations

While pain is a problem for PLWHA, it appears to be a greater problem in amaXhosa women living with HIV/AIDS (74% prevalence). Exploration of the characteristics and contributing factors to pain in amaXhosa women living with HIV/AIDS supports the adoption of the biopsychosocial model of pain in this group. In addition to exploring the characteristics and contributing factors to pain in HIV/AIDS, the biopsychosocial model was used to develop an intervention to manage pain in amaXhosa women living with HIV/AIDS. This was an intervention using education and exercise; which requires low resources making it applicable for use in a primary health care setting. The intervention designed for this study was well received by amaXhosa women living with HIV/AIDS and was effective in reducing pain in both those attending the full intervention and in those who only received the workbook.

This work presents a novel, feasible and effective biopsychosocial management approach for the problem of pain in PLWHA in resource-poor communities. Implementation of either the peer-led intervention or, of the workbook alone, should be encouraged as an acceptable method to increase accessibility to services in a population presently receiving limited or no treatment for pain. The acceptability of the intervention suggests that this model may be effective in diverse South African cultural and socio-economic groups. The translational mechanisms for the implementation of this work in partnership with departments of health, primary care clinicians and peer-leaders need to be identified and implemented.

Recommendations arising from this study can be evaluated in terms of clinical applicability and research recommendations. The clinical recommendations arising from this work include:

- The development of a specific protocol for the assessment and management of pain in PLWHA for use in all clinics which deal with HIV/AIDS.
  - This protocol should include guidelines for the routine assessment of pain in PLWHA at every consultation.
  - In addition, the guidelines should include the role of pharmacological and physiotherapy management of pain in PLWHA.
- Physiotherapy management should include
  - Screening of patients to determine if exercise may be safely prescribed followed by provision of the Positive Living workbook.
  - Printing and distribution of Positive Living workbooks to all physiotherapists working in clinics which deal with HIV/AIDS.
  - Physiotherapists at these clinics need to be trained in the self-management approach utilised in the workbooks.
  - Patients provided with the workbooks should be monitored monthly for a period of four months by the physiotherapist.

Recommendations for research arising from this work include studies to:

- Determine the prevalence of pain in amaXhosa men living with HIV/AIDS.
- Determine the prevalence of pain in amaXhosa living with HIV/AIDS in rural settings.
- Determine the acceptability and effectiveness of the “Positive Living” workbook in other groups of PLWHA in South Africa as it appears to offer a low cost and effective means of addressing pain and decreasing suffering in millions of PLWHA.
- Further explore variables contributing to specific sub-groups of pain in PLWHA with specific focus on
  - Headaches
  - Painful peripheral neuropathy
- Explore the effectiveness of non-pharmacological interventions in specific sub-groups of pain in PLWHA, specifically in
  - Headaches
  - Painful peripheral neuropathy

South Africa has approximately 5 million people living with HIV/AIDS. Based on the data in this thesis this means that between 2.8 and 3.7 million PLWHA in South Africa have pain; pain of sufficient severity to cause distress, pain which interferes with function and quality of life. Less than 1% of PLWHA are receiving adequate treatment for their pain. This translates to between 2.7 and 3.6 million PLWHA in South Africa not receiving adequate pharmacological treatment for their pain. There is a moral responsibility shared by health care professionals to ensure that all have access to pain management as a human right<sup>345</sup>. Ignoring the suffering of those in pain is problematic. The tragedy of the cumulative data in this thesis is that despite decades of research on pain in PLWHA it remains grossly under-treated.



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## Appendix A: Data for Systematic Review

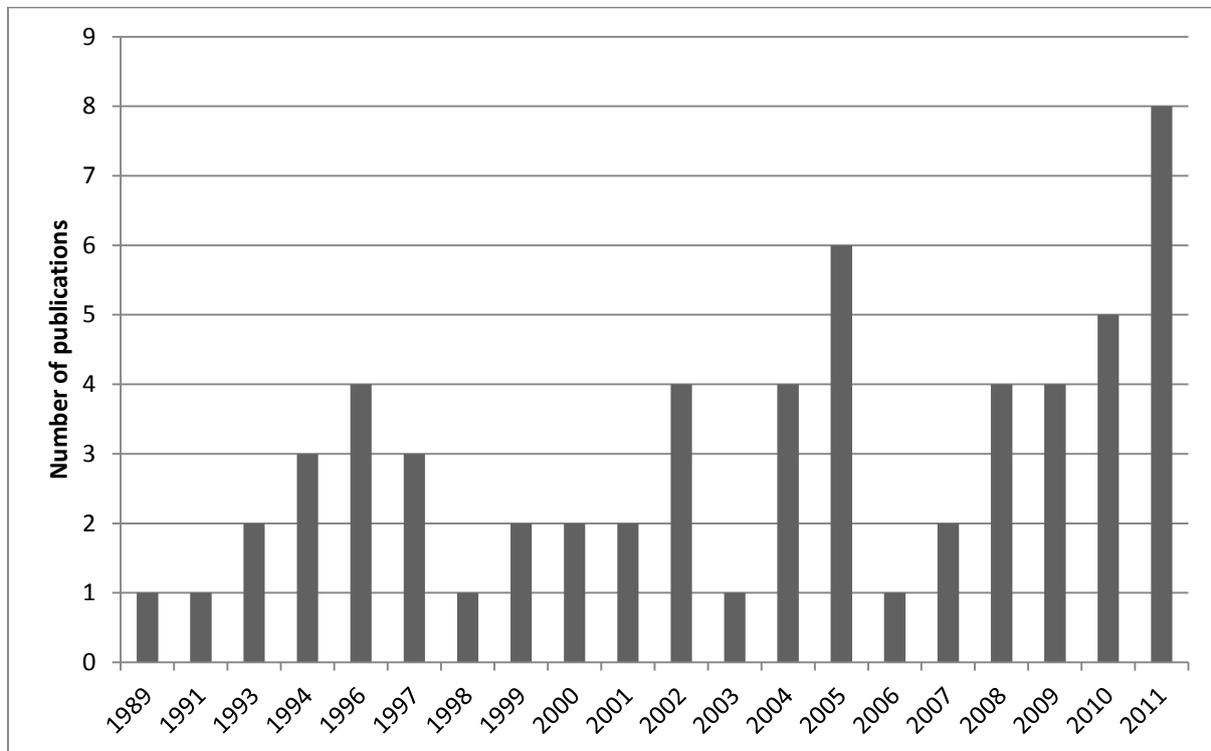


Figure A-1: Number of publications per year

Table A-1: Scores of all studies reviewed with the 11-item methodological appraisal tool

Year of publication reference	1. Entire target population/ randomly selected sample or a sample stated to represent the target population.	2. Non-responders	3. Response rate	4. Description of population.	5. Data primary data on the prevalence of pain in PLWHA?	6. The same mode of data collection.	7. Questionnaire/interview/examination validated or at least tested for reproducibility or adequately described and standardized	8. Data collected directly from the participant?	9. Precise description of what is meant by pain?	10. Further useful specification pain?	11. Prevalence recall periods stated.	SCORE (%)
1993 <sup>71</sup>	1	0	0	1	1	1	1	1	1	1	1	82
1994 <sup>72</sup>	1	1	0	1	1	1	1	0	0	1	1	73
2009 <sup>346</sup>	1	0	0	1	0	1	1	1	1	0	1	64
1996 <sup>14</sup>	0	1	1	1	1	1	1	1	1	1	1	91
1996 <sup>74</sup>	0	1	1	1	1	1	1	1	1	1	1	91
1997 <sup>73</sup>	0	0	0	1	1	1	1	1	1	1	1	73
1996 <sup>14</sup>	0	0	0	1	0	1	1	1	1	1	1	64
2010 <sup>347</sup>	1	0	0	1	0	1	1	1	1	0	1	64
2007 <sup>348</sup>	1	0	1	1	0	1	0	0	0	0	1	45
1997 <sup>6</sup>	1	1	0	1	1	1	1	1	1	1	1	91
1999 <sup>75</sup>	1	1	1	1	1	1	0	1	1	1	0	82
1991 <sup>349</sup>	1	1	N/A	1	0	1	0	0	0	1	1	55
2000 <sup>76</sup>	1	1	1	1	1	1	0	1	0	1	0	73
2000 <sup>77</sup>	1	1	1	1	0	1	0	1	0	1	1	73
1998 <sup>23</sup>	0	0	0	1	0	1	1	1	1	1	1	64
2010 <sup>350</sup>	1	0	0	1	0	1	0	1	0	0	1	45
2001 <sup>78</sup>	1	1	1	1	0	1	1	1	1	0	1	82
1997 <sup>351</sup>	1	N/A	N/A	1	1	1	0	0	0	1	1	67
2001 <sup>79</sup>	1	1	1	1	1	1	1	1	1	1	1	100

Year of publication reference	1. Entire target population/randomly selected sample or a sample stated to represent the target population.	2.Non-responders	3.Response rate	4. Description of population.	5. Data primary data on the prevalence of pain in PLWHA?	6. The same mode of data collection.	7. Questionnaire/interview/examination validated or at least tested for reproducibility or adequately described and standardized	8. Data collected directly from the participant?	9. Precise description of what is meant by pain?	10. Further useful specification pain?	11. Prevalence recall periods stated.	SCORE (%)
2008 <sup>352</sup>	1	0	0	1	0	1	1	1	0	1	1	64
2006 <sup>353</sup>	1	0	0	1	0	1	1	1	0	1	1	64
2002 <sup>80</sup>	1	0	1	1	0	1	1	1	0	1	1	73
2002 <sup>81</sup>	1	1	1	1	0	1	1	1	1	0	1	82
1994 <sup>354</sup>	1	N/A	N/A	1	0	1	1	0	0	1	1	67
2004 <sup>82</sup>	1	1	1	1	1	1	1	1	0	1	1	91
2005 <sup>355</sup>	1	0	0	1	0	1	1	1	0	0	0	45
1996 <sup>356</sup>	1	N/A	N/A	1	0	1	1	0	0	0	1	56
2004 <sup>83</sup>	1	0	0	1	0	1	1	1	1	1	1	73
2005 <sup>84</sup>	1	0	0	1	1	1	1	1	1	1	1	82
1989 <sup>357</sup>	1	1	1	1	1	0	0	0	0	1	1	64
1994 <sup>358</sup>	1	0	1	1	1	0	0	0	0	1	1	55
2005 <sup>85</sup>	1	1	1	1	0	1	1	1	1	1	1	91
2008 <sup>86</sup>	1	1	1	1	1	1	1	1	1	1	1	100
2009 <sup>87</sup>	1	1	0	1	0	1	1	1	0	1	1	73
2009 <sup>88</sup>	1	0	0	1	1	1	1	1	1	1	1	82
2009 <sup>89</sup>	1	1	1	1	1	1	0	1	1	0	1	82
2011 <sup>64</sup>	0	0	0	1	0	1	1	1	0	0	1	45
2010 <sup>90</sup>	1	1	0	1	1	1	1	1	0	1	1	82
2011 <sup>91</sup>	1	1	1	1	1	1	1	1	1	1	1	100

Year of publication reference	1. Entire target population/randomly selected sample or a sample stated to represent the target population.	2.Non-responders	3.Response rate	4. Description of population.	5. Data primary data on the prevalence of pain in PLWHA?	6. The same mode of data collection.	7. Questionnaire/interview/examination validated or at least tested for reproducibility or adequately described and standardized	8. Data collected directly from the participant?	9. Precise description of what is meant by pain?	10. Further useful specification pain?	11. Prevalence recall periods stated.	SCORE (%)
2002 <sup>359</sup>	1	0	0	0	1	1	1	1	0	1	1	64
2004 <sup>11</sup>	1	0	0	1	1	1	0	1	0	1	1	64
2010 <sup>360</sup>	1	0	0	1	0	1	1	1	0	0	1	55
2011 <sup>92</sup>	1	1	1	1	1	1	1	1	1	1	1	100
2008 <sup>254</sup>	1	1	1	1	0	1	0	1	0	0	1	64
2010 <sup>361</sup>	1	1	1	1	0	1	0	1	0	0	1	64
2011 <sup>15</sup>	1	N/A	N/A	1	1	1	1	1	1	1	1	100
2011 <sup>93</sup>	1	0	0	1	1	1	1	1	1	1	1	90
2005 <sup>255</sup>	1	N/A	N/A	1	0	1	1	1	0	0	1	67
2005 <sup>362</sup>	0	0	0	1	0	1	1	1	0	0	1	45
1993 <sup>363</sup>	0	0	0	1	1	1	1	0	0	1	1	55
2005 <sup>256</sup>	0	0	0	1	0	1	0	1	0	0	1	36
2011 <sup>94</sup>	1	1	1	1	0	1	1	1	0	0	1	73
2002 <sup>364</sup>	0	0	0	1	0	1	0	1	0	0	0	27
2007 <sup>365</sup>	0	0	0	1	0	1	0	1	0	0	0	27
2005 <sup>257</sup>	0	0	0	1	0	1	1	1	1	0	0	45
1999 <sup>366</sup>	0	0	0	1	0	1	1	1	0	0	1	45
2004 <sup>367</sup>	1	0	0	1	0	1	1	1	0	1	1	64
2003 <sup>368</sup>	1	0	0	1	0	1	1	1	0	1	1	64
2011 <sup>95</sup>	0	0	0	1	1	1	1	1	1	1	1	73

Year of publication reference	1. Entire target population/randomly selected sample or a sample stated to represent the target population.	2.Non-responders	3.Response rate	4. Description of population.	5. Data primary data on the prevalence of pain in PLWHA?	6. The same mode of data collection.	7. Questionnaire/interview/examination validated or at least tested for reproducibility or adequately described and standardized	8. Data collected directly from the participant?	9. Precise description of what is meant by pain?	10. Further useful specification pain?	11. Prevalence recall periods stated.	SCORE (%)	
2011 <sup>369</sup>		0	0	0	1	0	1	1	1	0	0	1	45
2008 <sup>370</sup>		1	0	0	1	0	1	0	1	0	0	1	45



# Appendix B: Letters of Ethical Approval



UNIVERSITY OF CAPE TOWN

Health Sciences Faculty  
Research Ethics Committee  
Room 157, 1st Floor, Science Building Old Main Building  
Observatory, 7925  
Telephone: 2014 201516 • Fax only: 2014 201511  
e-mail: HealthSci@uct.ac.za

17 April 2008

RFC REF: 420/2007

Ms Rita Parker  
PostHoc 3065  
5, 7th Floor  
Old Main Building

Dear Ms Parker

## **PROJECT TITLE: PAIN IN HIV/AIDS: CHARACTERISTICS, CONTRIBUTING FACTORS AND EFFECTS OF A 6-WEEK PEP-LED EXERCISE AND EDUCATION INTERVENTION.**

Thank you for inviting you to submit a Research Ethics Clearance application.

I am pleased to inform you that the Research Ethics Committee - format approval for human participants only has approved your application on 17 April 2008.

If the study is self-regulating please submit a progress report as to the research to the Research Ethics Committee.

Please will you submit your results for the Research Ethics Committee for publication in the journal of your choice as well as any queries regarding your rights and welfare.

The words to quote that the University of Cape Town Research Ethics Committee belongs to the FHS Standards for Clinical Research with a view to its inclusion in the Medical Research Council (MRC) 5th Edition and Drug Administration (DASA) 4th Edition International Convention on Human and Clinical Practice (ICHG-CCT) and Declaration of Helsinki guidelines.

The Research Ethics Committee regarding its approval is in compliance with the ICHG-4 Protocol, 4th Edition Guidelines 5th Note for Guidance on Good Clinical Practice (ICHG/GCP) (13/8/99) and FDA Code Federal Regulation Part 312.55 and 312.62.

To send this to you and a copy to the Research Ethics Committee.  
Treatment Review Panel (TRP) on date: 23/04/2008.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the RFC REF in all your correspondence.

Yours Sincerely

**DOREEN CLOONAN**  
**CHAIRPERSON, RESEARCH ETHICS**



Verwysing  
Reference  
Isalathiso  
19/18/RP12/2009

Navrae  
Enquiries  
Imibuzo  
Dr G Bernhardt

Telefoon  
Telephone  
Ifowuni  
021 483 9292

Departement van Gesondheid  
Department of Health  
ISebe lezeMpilo

Ms Romy Parker  
School of Health & Rehab Sciences  
F56 Old Main Building  
Observatory  
7925

FAX: 021 4066323

Dear Ms Parker

**Pain In HIV/AIDS: characteristics, contributing factors and the effects of a 6-week peer-led exercise and education intervention.**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following member of staff to assist you with access to the facility:

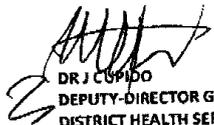
**Michael Mapongwana CHC: Mrs Jonas [nejonas@pgwc.gov.za](mailto:nejonas@pgwc.gov.za) Tel: 021 361 3353**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za)).
3. The reference number above should be quoted in all future correspondence.

We look forward to hearing from you.

Yours sincerely

  
DR J CUPIDO  
DEPUTY-DIRECTOR GENERAL  
DISTRICT HEALTH SERVICES AND PROGRAMMES  
DATE: 14-12-2009

CC: DR PEREZ

D: KHAYELITSHA & EASTERN SUB-STRUCTURE

## Appendix C: Translation records

Table C-1: Forward translation of the BPI

BPI English	BPI Xhosa (Translator A)	BPI Xhosa (Translator B)	BPI Xhosa Consensus Version (Version AB)	Comments
BRIEF PAIN INVENTORY	UKUHLOLWA KWEENGQAQAMBA	UKUHLOLWA KWEENGQAQAMBA	UKUHLOLWA KWEENGQAQAMBA	Both translators commented that there are several words in isiXhosa for pain. Both noted that they had used these words interchangeably through the questionnaire but agreed that the word ngqaqamba should be applied consistently throughout.
Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain during the last week?	Kubomi bethu sonke, uninzi lwethu lubaneentlubu amaxa amaninzi(ezinjenge ntloko ebuhlungu, ukukruneka, namazinyo abuhlungus). Ukukhe waza iitlungu ngaphandle kwezi sezikhankanyiwe kule veiki iphelileyo?	Kubomi bethu bonke, uninzi lwethu lube nokuqaqanjelwa (neentlungu), kumaxesha ngamaxesha (ezifana nentloko ebuhlungu ukukruneka, izinyo). Ukhe waqaqanjelwa ndaphandle kwezi ntlobo zengqaqambo kwisithuba seveki epheleleyo? Ukhe waneengqaqambo ezizezinye ngophandle kwezi zemihla ngemihla kule veiki iphelileyo?	Kubomi bethu bonke, uninzi lwethu lube nokuqaqanjelwa (neentlungu), kumaxesha ngamaxesha (ezifana nentloko ebuhlungu ukukruneka, izinyo). Ukhe waqaqanjelwa ndaphandle kwezi ntlobo zengqaqambo kwisithuba seveki epheleleyo? Ukhe waneengqaqambo ezizezinye ngophandle kwezi zemihla ngemihla kule veiki iphelileyo?	Translator A and B agreed that version B was grammatically correct while version A was more colloquial and while it would be understood by the younger generation version B was more appropriate for use across age groups.
Yes	Ewe	Ewe	Ewe	
No	Hai	Hai	Hai	

BPI English	BPI Xhosa (Translator A)	BPI Xhosa (Translator B)	BPI Xhosa Consensus Version (Version AB)	Comments
On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.	Kulo mfanekiso ulandelayo, bonisa indawo apho uva khona ubuhlungu, ubeka uphawu X apho kubuhlungu ngakumbi khona.	Kumzobo, zoba umthunzi kwimimandla (kwiindawo) apho uva iingqaqambo khona. Fakela u-X kummandla apho uva iingqaqambo kakhulu kuwo	Kulo mfanekiso ulandelayo, zoba umthunzi kwiindawo apho uva iingqaqambo khona. Fakela uphawu X apho uva iingqaqambo kakhulu khona.	A consensus version of A and B was agreed upon.
Please rate your pain by circling the one number that best describes your pain at its worst in the last week	Nceda ubonise ubungakanani beentlungu zakho, ngokurhangqa elona nani libonisa ubungakanani beentlungu ezo kule veki iphelileyo.	Nceda ulinganisele ukuqaqanjelwa kwakho ngokuthi urhangqe inani elithi lichaze ubungakanani bengqaqambo ozivayo xa <b>zukuphetha kakhulu</b> kule veki iphelileyo.	Nceda ulinganisele ukuqaqanjelwa kwakho ngokuthi urhangqe inani elithi lichaze ubungakanani bengqaqambo ozivayo xa <b>zukuphetha kakhulu</b> kule veki iphelileyo.	Agreement that version B was more grammatically correct and had closer meaning to the English.
No Pain	Akho ntlungu	Akukho zingqaqambo	Akukho zingqaqambo	Version B was chosen as being the consistent use of the term for pain selected to be used throughout.

BPI English	BPI Xhosa (Translator A)	BPI Xhosa (Translator B)	BPI Xhosa Consensus Version (Version AB)	Comments
Pain as bad as you can imagine	Kubuhlungu kakhulu	lingqambo ezingako onokuthi uzithelekelele	Lingqambo ezingako onokuthi uzithelekelele	Both translators felt that while the VAS with numbers would be understood by participants, the concept of a graded response is not part of Xhosa culture. Something either is present or it is not present, a person either feels something or they do not feel it. The concepts of being slightly happy vs. being happy may be difficult to grasp from a cultural context.
Please rate your pain by circling the one number that best describes your pain at its least in the last week.	Nceda ubonise ubungakanani beentlungu zakho, ngokurhangqa elona nani libonisa ubuncinci beentlungu ezo kule veki iphelileyo.	Nceda linganisela iingqambo zakho ngokurhangqa inani elinye elichaza kakuhle iingqambo zakho xa zikuphethe <b>kancinane</b> kule veki idlulileyo.	Nceda linganisela iingqambo zakho ngokurhangqa inani elinye elichaza kakuhle iingqambo zakho xa zikuphethe <b>kancinane</b> kule veki idlulileyo.	Consensus version reached based on correct grammar

BPI English	BPI Xhosa (Translator A)	BPI Xhosa (Translator B)	BPI Xhosa Consensus Version (Version AB)	Comments
Please rate your pain by circling the one number that best describes your pain on the average.	Nceda ubonise ubungakanani zakho	Nceda ulinganisele ubungakanani beengqaqambo zakho ngokuthi urhangqe inani elinye elizichaza ngcono iingqaqambo zakho <b>ngokomndilili.</b>	Nceda ulinganisele ubungakanani beengqaqambo zakho ngokuthi urhangqe inani elinye elizichaza ngcono iingqaqambo zakho <b>ngokomndilili.</b>	The issue of "average" pain was raised by both translators as being problematic in the same way as the VAS. While a Xhosa term for average does exist this relates only to the mathematical construct. Culturally both translators reflected that in Xhosa culture the term "average" would not have meaning. A person either has pain or does not have pain.
Please rate your pain by circling the one number that tells how much pain you have right now.	Nceda ubonise ubungakanani beentlungu onazo ngoku ngokurhangqela inani	Nceda linganisela iingqaqambo zakho ngokuthi urhangqe inani elinye elichaza ubungakanani bengqaqambo obuvayo <b>ngokwakaloku nje..</b>	Nceda linganisela iingqaqambo zakho ngokuthi urhangqe inani elinye elichaza ubungakanani bengqaqambo obuvayo <b>ngoku.</b>	Consensus version reached based on correct grammar and terminology
What treatments or medications are you receiving for pain?	Nyango luni olusebenzisayo ukuphelisa iintlungu?	Luluphi unyango okanye amayeza owafumanayo kwezi ngqaqambo?	Luluphi unyango okanye amayeza owasebenzisayo ukuphelisa iingqaqambo?	Consensus version agreed upon to include medications and treatments.

BPI English	BPI Xhosa (Translator A)	BPI Xhosa (Translator B)	BPI Xhosa Consensus Version (Version AB)	Comments
In the last week, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.	Kuleveki idlulileyo luncedo olungakanani olufumene kumayeza eentlungu, rhanqela i-percenatge ebonisa oko.	Kule veki iphelileyo, ufumene isiqabu esingakanani kunyango okanye kumayeza owanikiweyo? Nceda rhangqa ipesenti ethi ibonise ubungakanani besiqabu osifumeneyo.	Kule veki iphelileyo, ufumene isiqabu esingakanani kunyango okanye kumayeza owanikiweyo? Nceda rhangqa ipesenti ethi ibonise ubungakanani besiqabu osifumeneyo.	Version B was agreed upon as version A used colloquial language. Again translators highlighted the cultural challenge of asking for a response based on a graded scale. They expressed concern that responses would be classified at one end of the scale or the either in an "all or none" response.
No relief	Akukho siqabu	Akukho siqabu	Akukho siqabu	
Complete relief	Isiqabu esipheleleyo	Isiqabu esipheleleyo	Isiqabu esipheleleyo	
Circle the one number that describes how much, during the past week, pain has interfered with your:	Rhangqela inani elinye elibonisa indlela iintlungu ezithe zaphazamisana nokukulandelayo	Rhangqa inani elinye elichaza indlela <b>iingqaqambo</b> ezithe kule veki idlulileyo zaphazamisana ngayo:	Rhangqa inani elinye elichaza indlela <b>iingqaqambo</b> ezithe kule veki idlulileyo zaphazamisana ngayo:	Correct grammar with gender neutral interpretation - version B
Does not interfere	Ayiphazamisani	Azikhange zindiphazamise	Azikhange zindiphazamise	Version B selected as it more clearly identifies the extreme of the scale.
Completely interferes	Iyaphazamisa	Zindiphazamise ngokupheleleyo	Zindiphazamise ngokupheleleyo	Version B selected as it more clearly identifies the extreme of the scale.

BPI English	BPI Xhosa (Translator A)	BPI Xhosa (Translator B)	BPI Xhosa Consensus Version (Version AB)	Comments
General Activity	Okwenza imihla ngemihla	Nokusebenza kwakho ngokubanzi	Nokusebenza kwakho kwemihla ngemihla	Consensus of both versions
Mood	Nobume bomphefumlo	Nobume bomphefumlo	Nobume bomphefumlo	
Walking Ability	Ukuhamba	Nekhono lokuhamba	Nekhono lokuhamba	Version B selected as version A is the verb "to walk" while version B referred to "walking ability"
Normal Work (includes both work outside the home and housework)	Imisebenzi yasekhaya	Nomsebenzi wesiqhelo (kubandakanywa umsebenzi ongaphandle kwekhaya nowasendlwini)	Nomsebenzi wesiqhelo (kubandakanywa umsebenzi ongaphandle kwekhaya nowasendlwini)	Version B more accurate
Relations with other people	Ukuhlobana nabanye abantu	Nobudlelwana bam kunye nabanye abantu	Nobudlelwana bam kunye nabanye abantu	Version B selected as version A was agreed to be open to cultural misinterpretation
Sleep	Ululala	Nokulala	Nokulala	Correct grammar - Version B
Enjoyment of life	Ukonwabela ubomi	Nokonwabela ubomi	Nokonwabela ubomi	Correct grammar - Version B

Table C-2: Back translation of the BPI

BPI English	BPI Back translation (Translator C)	BPI Back Translation (Translator D)	Comments
BRIEF PAIN INVENTORY	EXAMINATION OF PAIN	ASSESSING THE SEVERITY OF PAIN LEVELS	
Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain during the last week?	In all our lives, the majority of us have experienced pain (pains), from time to time (like headache, sprain, and toothache). Have you experienced other types of pain besides these ones during last week? Have you experienced other pains other than the daily one during last week?	In all of our lives, many have often had to endure pains (and suffering), like headaches, muscle stretching, toothache. Did you experience ant pain other than those above in the past week? Did you experience any pains different to those you are accustomed to in the past week?	All agreed that the meaning and intent of the original question was maintained.
Yes	Yes	Yes	
No	No	No	
On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.	In the following picture draw a shadow where you feel pain. Place / Insert X where you feel the most pain.	In the picture below, shade the spot where you experience pain. Put an X where there is more pain.	The term shadow used was a direct translation, interpretation by translator D correct.
Please rate your pain by circling the one number that best describes your pain at its <b>worst</b> in the last week.	Please indicate the severity of your pain by encircling the number which indicates that severity when you experienced most pain last week.	Please rate your levels of pain by circling the number that correctly defines your worst levels of pain over the past week.	All agreed that the meaning and intent of the original question was maintained.
No Pain	No Pain	No Pains	
Pain as bad as you can imagine	The most severe pain you can imagine	Too much pain	Again all translators found it difficult to work with grades or levels of pain as in Xhosa culture something is present or it is not present.

BPI English	BPI Back translation (Translator C)	BPI Back Translation (Translator D)	Comments
Please rate your pain by circling the one number that best describes your pain at its <b>least</b> in the last week.	Indicate the least pain felt by encircling the number which indicates that least severity last week.	Please rate your levels of pain by circling the number that correctly defines your least levels of pain over the past week.	
Please rate your pain by circling the one number that best describes your pain on the <b>average</b> .	Please indicate the intensity of your pain by encircling the number which indicates the average intensity of your pain.	Please circle the number that correctly defines your overall levels of pain.	Again the issue of average was raised. This term not used/understand. All translators highlighted that this question may need to be removed
Please rate your pain by circling the one number that tells how much pain you have <b>right now</b> .	Please indicate pain you presently feel by encircling the number which indicates pain presently felt.	Please circle the number that correctly defines your levels of pain at this moment	
What treatments or medications are you receiving for your pain?	What treatment or medication do you use to relieve pain?	What treatment or medication are you using to ease the pains?	The question was interpreted in terms of medications used rather than medications received. Translators felt that this could not be termed in a different way and emphasis on the way it was verbally asked would influence interpretation.
In the last week, how much <b>relief</b> have pain treatments or medications provided? Please circle the one percentage that most shows how much <b>relief</b> you have received.	How much relief did you get last week as a result of treatment or medication obtained? Circle the percentage which indicates the level of relief you obtained.	How much pain relief did you experience as a result of the treatment or medication you have been given. Please circle the percentage showing level of relief you have experienced.	Percentage may present a challenge. The concept of percentages may be difficult, the term how much better challenging. Very difficult - pain is pain
No relief	No relief	No relief	
Complete relief	Total relief	Perfect relief	

BPI English	BPI Back translation (Translator C)	BPI Back Translation (Translator D)	Comments
Circle the one number that describes how much, during the past week, pain has <b>interfered with</b> your:	Circle one number which indicates how pain interfered with you during the past week, with regard to	Circle the number that describes how the pains interfered with:	
<b>General activity</b>	<b>Your general daily activities</b>	<b>Your daily work or chores</b>	
Did not interfere at all	Did not interfere with me	No delays	No delays a direct translation which is interpreted as no problems
<b>Completely interferes</b>	<b>Fully interfered with me</b>	<b>100% disturbances</b>	
Mood	Mood	Your spiritual life	Spiritual life is a literal translation as there is no Xhosa word for "mood", this will be interpreted to mean mood or spiritual health
<b>Walking ability</b>	<b>walking</b>	<b>the ability to walk</b>	
Normal work (includes both work outside the home and housework)	Normal work (including work inside and outside household)	The normal workload (mention both domestic and outdoor work)	
<b>Relations with other people</b>	<b>Relations with other people</b>	<b>My relationship with other people</b>	
Sleep	Sleep	Sleeping	
Enjoyment of life	Enjoyment of life	Enjoying life	

Table C-3: Forward translation of the CTQ-SF

CTQ English	CTQ Xhosa (Translator A)	CTQ Xhosa (Translator B)	CTQ Xhosa Consensus Version (AB)	Comments
Title: Childhood Trauma Questionnaire – Short Form (CTQ-SF)	Uluhlu lwemibuzo ngokwenzakala ebuntwaneni – Ukunqunyulelwa (CTQ-SF)	Uluhlu lwemibuzo ngokwenzakala ebuntwaneni – Ukunqunyulelwa (CTQ-SF)	Uluhlu lwemibuzo ngokwenzakala ebuntwaneni – Ukunqunyulelwa (CTQ-SF)	Direct translation of the title.
Instructions: These questions ask about some of your experiences growing up as a child and a teenager. For each question, circle the number that best describes how you feel. Although some of these questions are of a personal nature, please try to answer as honestly as you can. Your answers will be kept confidential.	Imiyalelo: Le mibuzo ikubuzamalunga namava akho ekukhuleni kwakho njengomntwana naxa sele ufikisa. Kumbuzo ngamnye, rhangqa inani elichaza ngokwaneleyo indlela oziva ngayo. Nangona eminye imibuzo ikubuzangezinto ongathandi zaziwe, zama ukuyiphendula ngokunyaniseka kangangoko unakho. Iimpendulo zakho ziya kugcinwa ziyimfihlo.	Imiyalelo: Le mibuzo ikubuzamalunga namava akho ekukhuleni kwakho njengomntwana naxa sele ufikisa. Kumbuzo ngamnye, rhangqa inani elichaza ngokwaneleyo indlela oziva ngayo. Nangona eminye imibuzo ikubuzangezinto ongathandi zaziwe, zama ukuyiphendula ngokunyaniseka kangangoko unakho. Iimpendulo zakho ziya kugcinwa ziyimfihlo.	Imiyalelo: Le mibuzo ikubuzamalunga namava akho ekukhuleni kwakho njengomntwana naxa sele ufikisa. Kumbuzo ngamnye, rhangqa inani elichaza ngokwaneleyo indlela oziva ngayo. Nangona eminye imibuzo ikubuzangezinto ongathandi zaziwe, zama ukuyiphendula ngokunyaniseka kangangoko unakho. Iimpendulo zakho ziya kugcinwa ziyimfihlo.	Agreement
Never True (1)	Akuynyani komnke	Akuzange kub e yinyaniso	Akuynyani komnke	Version A more absolute than B

CTQ English	CTQ Xhosa (Translator A)	CTQ Xhosa (Translator B)	CTQ Xhosa Consensus Version (AB)	Comments
Rarely True (2)	Kuyinyani kancinci	Akufane kube yinyaniso	Akufane kube yinyaniso	Version B agreed to, Translator A found this difficult. In Xhosa there is no in-between, its either true or not true. Although can translate it may not be responded to as people won't relate to that kind of response
Sometimes True (3)	Maxawambi kuyinyani	Ngmanyane amaxesha kuyinyanisogo	Maxawambi kuyinyani	Both translations mean the same but A is more concise.
Often True (4)	Kuyinyani kumatyeli aliqela	Kusoloko kuyinyaniso	Kusoloko kuyinyaniso	Same meaning but version B more concise.
Very Often True (5)	kuyinyani maxawonke	Kumaxesha amaninzi kuyinyaniso	Kuyinyani maxawonke	Version A agreed to as more concise but again very difficult to interpret in Xhosa culture.
When I was growing up, ...	Xa ndandikhula	Ngokuya ndandikhula, ...	Ngokuya ndandikhula, ...	Both have the same meaning and are interchangeable but both translators agreed that if the questionnaire is being read to people then version B is more suitable.

CTQ English	CTQ Xhosa (Translator A)	CTQ Xhosa (Translator B)	CTQ Xhosa Consensus Version (AB)	Comments
1. I didn't have enough to eat.	1. Ndandingena kutya nkwaneleyo	1. Andizange ndibe nentonyoktya eyaneleyo.	1. Andizange ndibe nentonyoktya eyaneleyo.	Version B agreed to as it will read more comfortably
2. I knew there was someone to take care of me and protect me	2. Ndandisazi ukuba kukho umntu ozakundikhathalela andikhusele	2. Ndandisazi ukuba kukho umntu wokundinlonga nokundikhusela	2. Ndandisazi ukuba kukho umntu ozakundikhathalela andikhusele	Version A agreed to as the language is less formal, more colloquial and will be easier to understand across the board with regard to levels of education.
3. People in my family called me things like "stupid", "lazy", or "ugly".	3. Abantu bosapho lwam babendibiza ngezinyeliso ezinje-'usisibhanxa', "ulingenerha" okanye "ndimbi"	3. Abantu kusapho lwam babendibiza ngamagama afana "ukuba sisidenge", "ukunqena", okanye "ukuba mbi".	3. Abantu kusapho lwam babendibiza ngamagama afana nokuba "sisidege", "inqenerha" okanye "ukuba mbi"	Amalgamation of the two versions. Initial parts of the sentence the same but terms for stupid, lazy and ugly adjusted to simplify language
4. My parents were too drunk or high to take care of me.	4. Abazali bam babenxila okanye beyobekile kakhulu ukuba bandikhathalele	4. Abazali bam babenxila kakhulu okanye betye iziyobisi ukuba bangandilolonga.	4. Abazali bam babenxila kakhulu okanye betye iziyobisi ukuba bangandikhathalele	B is more explicit than A, compromise of the two gives a translation which explains what "being high" means
5. There was someone in my family who helped me feel important or special.	5. Kwakukho umntu wosapho lwam owandinceda ndaziva ndibalulekile.	5. Kwakukho umntu kusapho lwam owayendinceda ndizive ndibalulekile okanye ndingumntu nje oyedwa.	5. Kwakukho umntu kusapho lwam owayendinceda ndizive ndibalulekile okanye ndingumntu nje oyedwa.	Version B agreed to as A's sentence is grammatically incomplete
6. I had to wear dirty clothes.	6. Kwakufuneka ndinxibe impahla emdaka.	6. Kwakufuneka ndinxibe impahla emdaka.	6. Kwakufuneka ndinxibe impahla emdaka.	Both translators had same wording

CTQ English	CTQ Xhosa (Translator A)	CTQ Xhosa (Translator B)	CTQ Xhosa Consensus Version (AB)	Comments
7. I felt loved.	7. Ndandiziva ndithandwa.	7. Ndandiziva ndithandwa.	7. Ndandiziva ndithandwa.	Both translators had same wording
8. I thought that my parents wished I had never been born.	8. Ndandicinga ukuba abazali bam babenqwena ukuba zange ndizalwe	8. Ndandicinga ukuba abazali bam babelangazelela ukuba ndibe andizange ndizalwe.	8. Ndandicinga ukuba abazali bam babelangazelela ukuba ndibe andizange ndizalwe.	Each translator used a different word for "wish" - synonyms. Agreed to use version B.
9. I got hit so hard by someone in my family that I had to see a doctor or go to the hospital.	9. Ndabethwa kakhulu ngumntu kusapho lwam kwade kwafuneka ndibonane nogqirha okanye ndiye esibhedlele.	9. Ndabethwa kakhulu ngumntu kusapho lwam kwade kwafuneka ndibonane nogqirha okanye ndiye esibhedlele.	9. Ndabethwa kakhulu ngumntu kusapho lwam kwade kwafuneka ndibonane nogqirha okanye ndiye esibhedlele.	Same
10. There was nothing I wanted to change about my family.	10. Bekungekho nto ndifuna ukuyiguqula ngosapho lwam	10. Kwakungekho nto ndandifuna ukuyitshintsha kusapho lwam.	10. Kwakungekho nto ndandifuna ukuyiguqula kusapho lwam.	An amalgamation of the two versions agreed to by the translators.
11. People in my family hit me so hard that it left bruises or marks.	11. Abantu bosapho lwam babendibetha kakhulu ndide ndibenezivubeko	11. Abantu kusapho lwam bandibetha kakhulu ndatsho ndashiyeka ndineziva okanye imivambo.	11. Abantu kusapho lwam bandibetha kakhulu ndatsho ndashiyeka ndineziva okanye imivambo.	Agreed to use version B as the wording is less specific to bruising and includes a broader range of injury such as marks, scratches or bruises.
12. I was punished with a belt, a board, a cord, or some hard object.	12. Ndandisohlwaywa ngebhanti, iplanga, intambo, okanye nayiphi na into eqinileyo.	12. Ndandisohlwaywa ngebhanti, iplanga, intambo, okanye nayiphi na into eqinileyo.	12. Ndandisohlwaywa ngebhanti, iplanga, intambo, okanye nayiphi na into eqinileyo.	Both versions the same

CTQ English	CTQ Xhosa (Translator A)	CTQ Xhosa (Translator B)	CTQ Xhosa Consensus Version (AB)	Comments
13. People in my family looked out for each other.	13. Abantu bosapho lwam babekhathalelene.	13. Abantu bosapho lwam babekhathalelene.	13. Abantu bosapho lwam babekhathalelene.	Translators had used the same wording. This is not a direct translation but a translation of the meaning to care for each other.
14. People in my family said hurtful or insulting things to me.	14. Abantu bosapho lwam babendithuka okanye bendenyelisa	14. Abantu kusapho lwam babethetha izinto ezihlupha umphefumlo nezithukayo.	14. Abantu bosapho lwam babendithuka okanye bendenyelisa	While both have the same meaning, translators agreed to use version A as the language is more colloquial and will have broader understanding across age groups.
15. I believe that I was physically abused.	15. Ndikholelwa ukuba ndahlukunyezwa emzimbeni.	15. Ndiyakholelwa ukuba ndaxhatshazwa ngokubethwa.	15. Ndiyakholelwa ukuba ndaxhatshazwa ngokubethwa.	Version B selected as A has a Zulu word in it. This is a reflection of his own background of mixed cultures. While his parents are both Xhosa they come from an area bordering on Zulu groups and language has become mixed. Both Xhosa and Zulu are belong to the Nguni language group and have structural similarity

CTQ English	CTQ Xhosa (Translator A)	CTQ Xhosa (Translator B)	CTQ Xhosa Consensus Version (AB)	Comments
16. I had the perfect childhood.	16.. Ndandinobuntwana obugqibeleleyo	16. Ndibe nobomi obufezekileyo ebuntwaneni.	16. Ndibe nobomi obufezekileyo ebuntwaneni.	Translations essentially have the same meaning, B agreed to as reads better when coupled with the introductory sentence leading into all these statements.
17. I got hit or beaten so badly that it was noticed by someone like a teacher, neighbour, or doctor.	17r.Ndabethwa kangangokuba yade yaqatshelwa ngutitshala, ummelwane okanye ugqirha..	17. Ndandinqindwa okanye ndibethwe kakhulu kude kubonwe nangomnye umntu ofana notitshala, ummelwane, okanye ugqirha.	17. Ndandinqindwa okanye ndibethwe kakhulu kwade kwaqatshelwa nangomnye umntu ofana notitshala, ummelwane, okanye ugqirha.	Created a synthesis of both versions
18. I felt that someone in my family hated me.	18. Kwakuvakala ngathi kukho umntu ondicaphukelayo kusapho lwam	18. Ndandicinga ukuba ukho umntu ongandithandiyo kusapho lwam.	18. Ndandicinga ukuba ukho umntu ongandithandiyo kusapho lwam.	In A's translation the meaning refers to feeling as an emotion, B's refers to thoughts and feelings, as in "I thought or felt that someone hated me". Version B agreed to as it was felt to be a more complete translation of the meaning of the statement

CTQ English	CTQ Xhosa (Translator A)	CTQ Xhosa (Translator B)	CTQ Xhosa Consensus Version (AB)	Comments
19. People in my family felt close to each other.	19. Abantu bosapho lwam babe sondelene kakhulu	19. Abantu kusapho lwam babethandana.	19. Abantu kusapho lwam babethandana.	This was difficult. B's translation refers to loving each other and feeling close while A's has used cared for each other. There is no translation for closeness. Translators agreed to use B's version as the word "babethandana" encompasses the idea of caring.
20. Someone tried to touch me in a sexual way, or tried to make me touch them.	20. Kukho umntu owazama ukundibamba ngendlela yokufuna isondo okanye wazama ukundinyanzela ukuba ndiphatha phathe	20. Umntu wazama ukundibamba-bamba ngendlela apha ebonisa ukufuna isondo, okanye wazama ukuba ndimbambe yona.	20. Kukho umntu owazama ukundibamba-bamba ngendlela apha ebonisa ukufuna isondo, okanye wazama ukuba ndimphathaphathe.	This was very difficult and the translators agreed to a synthesised version. It was very difficult to translate into Xhosa as sexual matters are essentially silent in the language. Touching someone doesn't have any sexual connotation – this statement will imply a sexual connotation.

CTQ English	CTQ Xhosa (Translator A)	CTQ Xhosa (Translator B)	CTQ Xhosa Consensus Version (AB)	Comments
21. Someone threatened to hurt me or tell lies about me unless I did something sexual with them.	21. Kukho umntu owandithembisa ngokundenzakalisa okanye axoke ngam ngaphandle kokuba ndeze okwesondo naye	21. Wandisongela ngokundenzakalisa okanye athethe ubuxoki ngam ngaphandle kokuba ndabelane ngesondo naye.	21. Wandisongela ngokundenzakalisa okanye athethe ubuxoki ngam ngaphandle kokuba ndabelane ngesondo naye.	Version B selected as the wording is more comfortable for a reader.
22. I had the best family in the world.	22. Ndadinosapho olugqibeleleyo kwihlabathi lonke	22. Ndibe nosapho olulunge kakhulu kwilizwe lonke.	22. Ndadinosapho olugqibeleleyo kwihlabathi lonke	Use A's as it emphasises a perfect family and when spoken sounds better.
23. Someone tried to make me do sexual things or make me watch sexual things.	23. Kukho umntu owazama ukundenza izimanga okanye andinyanzele ukuba ndibukele izinto ezidibene nesondo	23. Wazama ukuba ndenze izenzo zokwabelana ngesondo okanye ndibukele izinto zokwabelana ngesondo.	23. Wazama ukuba ndenze izenzo zokwabelana ngesondo okanye wandinyanzela ukuba ndibukele izinto zokwabelana ngesondo.	Translators synthesised the two versions.
24. Someone molested me.	24. Kukho umntu owandinyukunyeza ngokwesondo	24. Wandixhaphaza.	24. Wandixhaphaza.	B's selected as this meaning has sexual and non-sexual inferences. A's term is always sexual however it is not a commonly used term and may not be familiar to everyone.
25. I believe that I was emotionally abused.	25. Ndikholelwa ukuba ndahlukunyezwa ngokomphefumlo	25. Ndiyakholwa ukuba ndxhatshazwa ngokwasemphefumleni.	25. Ndiyakholwa ukuba ndxhatshazwa ngokwasemphefumleni.	Use B's as A's has strong Zulu influence and will be recognised as Zulu.

CTQ English	CTQ Xhosa (Translator A)	CTQ Xhosa (Translator B)	CTQ Xhosa Consensus Version (AB)	Comments
26. There was someone to take me to the doctor if I needed it.	26. Kwakukho umntu wokundisa kwagqirha ukuba ndandidinga oko.	26. Wayesoloko ekho umntu wokundithatha andise kugqirha xa kuyimfuneko.	26. Wayesoloko ekho umntu wokundithatha andise kugqirha xa kuyimfuneko.	B's emphasises that there was <i>always</i> someone available. This version also less formal
27. I believe that I was sexually abused	27. Ndikholelwa ukuba ndahlukunyezwa ngokwesondo.	27. Ndiyakholwa ukuba ndaxhatshazwa ngokwesondo.	27. Ndiyakholwa ukuba ndaxhatshazwa ngokwesondo.	Translators again found this difficult due to the nature of sexual references being silent in Xhosa. B's version was felt to be better as it is less formal than A's.
28. My family was a source of strength and support.	28. Usapho lwam belungamandla kum kwaye lundixhasa	28. Usapho lwam belungumthombo wamandla nenkxaso kum.	28. Usapho lwam belungamandla kum kwaye lundixhasa	Both had same meaning but agreed to use A's as it was easier to understand in terms of emotional strength and support.

Table C-4: Back translation of the CTQ-SF

CTQ English	CTQ Back translation (Translator C)	CTQ Back Translation (Translator D)	Comments
Title: Childhood Trauma Questionnaire – Short Form (CTQ-SF)	The short childhood trauma questionnaire	The short version of the childhood trauma questionnaire	
Instructions: These questions ask about some of your experiences growing up as a child and a teenager. For each question, circle the number that best describes how you feel. Although some of these questions are of a personal nature, please try to answer as honestly as you can. Your answers will be kept confidential.	Instructions: These questions ask about some of the things that happened when you were a child. In each question circle the number that describes how you feel. Some of the questions are personal but please answer as honest as possible. Your answers will be kept in confidence.	Instructions: These questions are about some of the things which might have happened when you were a child. Circle the number in each question that describes how you feel. Please answer the questions honestly even though they are personal. Your answers will be confidential.	
Never True (1)	Never True	Never True	
Rarely True (2)	Rarely true	Rarely true	For all these responses the translation committee felt that responses would be difficult. While semantic meaning of the range of “true” was found, culturally the interpretation might be challenging with cultural responses being “true” or “not true” and grades of true or perceived “grey areas” not being understood by the respondents. The translators emphasised that analysis of these responses may reveal responses on either end of the scale.

CTQ English	CTQ Back translation (Translator C)	CTQ Back Translation (Translator D)	Comments
Sometimes True (3)	Sometimes true	Sometimes true	
Often True (4)	Often true	Often true	
Very Often True (5)	Very often true	Very often true	
When I was growing up, ...	When I was becoming an adult	When I was growing	
1. I didn't have enough to eat.	I didn't have enough to eat	I didn't have enough food	
2. I knew there was someone to take care of me and protect me	I knew there was someone who cared for me and would protect me	I knew someone would care and protect me	
3. People in my family called me things like "stupid", "lazy", or "ugly".	People in my family called me things like "stupid", "lazy" or "ugly"	People in my family called me things like "stupid", "lazy" or "ugly"	
4. My parents were too drunk or high to take care of me.	My parents were too drunk or on drugs and couldn't take care of me.	My parents were too drunk or were high with drugs so couldn't take care of me.	
5. There was someone in my family who helped me feel important or special.	There was someone in my family who made me feel special	Someone in my family who helped me feel important or special	Committee commented here that the term used for family in isiXhosa is broader than the Western concept of family. This may refer to people within an extended network of caring, the similarity however was acknowledged that this would refer to trusted relationships.
6. I had to wear dirty clothes.	I had dirty clothes to wear	I had to wear dirty clothes	
7. I felt loved.	I felt loved	I felt loved	
8. I thought that my parents wished I had never been born.	I thought my parents wished I had never been born.	I thought that my parents wished I had never been born.	
9. I got hit so hard by someone in my family that I had to see a doctor or go to the hospital.	Someone in my family hit me so hard that I had to see a doctor or go to the hospital.	I was hit so hard by someone in my family that I had to see a doctor or go to the hospital	

CTQ English	CTQ Back translation (Translator C)	CTQ Back Translation (Translator D)	Comments
10. There was nothing I wanted to change about my family.	I would not change anything about my family.	There was nothing I would change about my family.	
11. People in my family hit me so hard that it left bruises or marks.	People in my family hit me so hard that it left bruises or made marks.	People in my family hit me so hard that I had bruises or marks	
12. I was punished with a belt, a board, a cord, or some hard object.	I was punished with a belt, board, cord or other hard object	I was punished with a belt, board, cord or other hard object	
13. People in my family looked out for each other.	People in my family looked after each other.	People in my family cared about each other.	
14. People in my family said hurtful or insulting things to me.	People in my family said things that were hurtful or insulting to me.	People in my family insulted me and said hurtful things.	
15. I believe that I was physically abused.	I believe I was physically abused.	I believe that I was physically abused.	
16. I had the perfect childhood.	My life as a child was perfect	I had a perfect childhood	
17. I got hit or beaten so badly that it was noticed by someone like a teacher, neighbour, or doctor.	I was beaten so badly that someone like my teacher, neighbour or doctor noticed it.	I got hit or beaten so badly that it was noticed by someone like a teacher, neighbour or doctor.	
18. I felt that someone in my family hated me.	I thought or felt that someone in my family hated me.	I had thoughts and feelings that someone in my family hated me.	
19. People in my family felt close to each other.	People in my family loved and cared for each other.	People in my family cared for each other.	

CTQ English	CTQ Back translation (Translator C)	CTQ Back Translation (Translator D)	Comments
20. Someone tried to touch me in a sexual way, or tried to make me touch them.	Someone tried to touch me or make me touch them in sexual ways.	Someone molested me.	Translator D was a young female with experience in translating materials around sexual harassment. Her interpretation of this wording was as molestation and she reported that in young urban females this was the colloquial wording used for molestation – a term which has no direct isiXhosa equivalent.
21. Someone threatened to hurt me or tell lies about me unless I did something sexual with them.	Someone threatened me with harm or would tell lies about me if I did not do sexual acts with them.	Someone threatened to hurt me or lie about me if I did not do something sexual with them.	
22. I had the best family in the world.	I had the best family in the world	I had the best family in the world	
23. Someone tried to make me do sexual things or make me watch sexual things.	Someone tried to get me to do sexual things or watch sexual things with them	Someone tried to make me do sexual things or watch sexual things.	
24. Someone molested me.	Someone raped me.	Someone molested me	This was difficult to equate. The terms molestation and rape have different meanings but the isiXhosa vocabulary is limited and Translator C (male in his 60's) reported that in his social group there was not a word appropriate for rape. The other 3 translators (2 women, 1 male in his 20's) agreed that the colloquial terms used referred to the term molestation and not the more restricted term of rape.

CTQ English	CTQ Back translation (Translator C)	CTQ Back Translation (Translator D)	Comments
25. I believe that I was emotionally abused.	I believe I was emotionally abused.	I believe I was emotionally abused.	
26. There was someone to take me to the doctor if I needed it.	There was always someone to take me to the doctor if I needed.	There was someone to take me to the doctor if I needed to go.	
27. I believe that I was sexually abused	I believe I was raped.	I believe I was sexually abused.	Again the limited Xhosa vocabulary for sexual terms and its interpretation was highlighted. Translator C was unfamiliar with this language as in his age set the terms are not used or referred to. The female translators and younger male all felt that the terms used were colloquially acceptable and had the correct meaning. Translators all emphasised that these sexual questions must be asked by an interviewer of the same gender as the patient and that age must be considered as conversing on these topics outside of an age set would be very uncomfortable.
28. My family was a source of strength and support.	My family supported and cared for me and gave me strength.	My family gave me strength and support.	

Table C-5: Forward translation of the SE-6

SE-6 English	SE-6 Xhosa (Translator A)	SE-6 Xhosa (Translator B)	SE-6 Xhosa Consensus Version	Comments
Self-Efficacy for Managing Chronic Disease 6-Item Scale	Not translated.	Ubuchule onabo bokuLawula iSifo esingapheliyo isikali esinamabanga ama-6	Ubuchule onabo bokuLawula iSifo esingapheliyo isikali esinamabanga ama-6	Challenging for Translator A – possibly a reflection of training as OT in English influencing his ability to express himself technically in Xhosa
We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.	Sifuna ukwazi ukuba uzithembe kangakanani ekwenzeni izinto ezithile. Kule mibuzo ilandelayo, nceda ukhethe inani elingqinelana nokuzithemba kwakho ekwenzeni ezizinto zilandelayo.	Singathanda ukwazi ukuba uqiniseke kangakanani ekwenzeni imisebenzi ethile. Kumbuzo ngamnye kule ilandelayo, nceda ukhethe inani elithi lihambelane nokuqiniseka kwakho ngento yokuba unakho ukuyenza le misebenzi qho ngoku.	Singathanda ukwazi ukuba uqiniseke kangakanani ekwenzeni izinto ezithile. Kumbuzo ngamnye kule ilandelayo, nceda ukhethe inani elithi lihambelane nokuqiniseka kwakho ngento yokuba unakho ukuzenza ezizinto zilandelayo	Translators came up with a synthesised version to contextualize the question and for consistent grammatical structure. The person who is conducting the questionnaire needs to have a very good concept of what self-efficacy is about as verbal intonation may change the meaning of the question.
not at all confident	Andizithemba kwaphela	Andiqinisekanga konke konke	Andiqinisekanga konke konke	A's use of wording direct translation of confidence, B's is more comfortable verbally. Agreed to use B's.
totally confident	Ndizithembe ngokugqibeleleyo	Ndiqine seke ngokupheleleyo	Ndiqine seke ngokupheleleyo	As for above

SE-6 English	SE-6 Xhosa (Translator A)	SE-6 Xhosa (Translator B)	SE-6 Xhosa Consensus Version	Comments
1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	1. Uqiniseke kangakanani ngento yokuba unakho ukunqanda ukudinwa okubangelwa sisigulo sakho ekuphazamisaneni nezinto ofuna ukuzenza?	1. Uqiniseke kangakanani ngento yokuba unakho ukulawula ukudinwa okubangelwa sisigulo sakho ekuphazamisaneni nezinto ofuna ukuzenza?	1. Uqiniseke kangakanani ngento yokuba unakho ukunqanda ukudinwa okubangelwa sisigulo sakho ekuphazamisaneni nezinto ofuna ukuzenza?	In translation, A's wording refers to "prevent" whereas B's is more "control".
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	2. Uqiniseke kangakanani ngento yokuba unakho ukuthintela ubunzima obusemzimbeni okanye iingqaqambo zesigulo sakho ekuphazamisaneni nezinto ofuna ukuzenza?	2. Uqiniseke kangakanani ngento yokuba unakho ukubugcina ubunzima obusemzimbeni okanye iingqaqambo zesigulo sakho ekuphazamisaneni nezinto ofuna ukuzenza?	2. Uqiniseke kangakanani ngento yokuba unakho ukuthintela ubunzima obusemzimbeni okanye iingqaqambo zesigulo sakho ekuphazamisaneni nezinto ofuna ukuzenza?	Synonyms used for the word pain, Version A accepted as it was felt to encompass discomfort and pain as opposed to Version B which was felt to focus on pain only.
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	3. Uqiniseke kangakanani ngento yokuba unakho ukuthintela ukuxhwaleka ngokwasemphefumleni okubangelwa sisigulo sakho ekuphazamisaneni nezinto ofuna ukuzenza?	3. Uqiniseke kangakanani ngento yokuba unakho ukukugcina ukuxhwaleka ngokwasemphefumleni okubangelwa sisigulo sakho ekuphazamisaneni nezinto ofuna ukuzenza?	3. Uqiniseke kangakanani ngento yokuba unakho ukuthintela ukuxhwaleka ngokwasemphefumleni okubangelwa sisigulo sakho ekuphazamisaneni nezinto ofuna ukuzenza?	Difficulty with the words "emotional distress" so had to find words relating to spiritual distress which would be understood to mean emotional. Version A felt to have best meaning.
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	4. Uqiniseke kangakanani ngento yokuba unakho ukuthintela ezinye iimpawu okanye iingxaki zempilo onazo ekuphazamisaneni nezinto ofuna ukuzenza?	4. Uqiniseke kangakanani ngento yokuba unakho ukugcina ezinye iimpawu okanye iingxaki zempilo onazo ekuphazamisaneni nezinto ofuna ukuzenza?	4. Uqiniseke kangakanani ngento yokuba unakho ukuthintela ezinye iimpawu okanye iingxaki zempilo onazo ekuphazamisaneni nezinto ofuna ukuzenza?	

SE-6 English	SE-6 Xhosa (Translator A)	SE-6 Xhosa (Translator B)	SE-6 Xhosa Consensus Version	Comments
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?		5. Uqiniseke kangakanani ngento yokuba unakho ukwenza imisebenzi edingekayo ukulawula ubume bempilo yakho ukulungiselela ukunciphisa isidingo sakho sokubonana nogqirha?	5. Uqiniseke kangakanani ngento yokuba unakho ukwenza imisebenzi edingekayo ukulawula ubume bempilo yakho ukulungiselela ukunciphisa isidingo sakho sokubonana nogqirha?	A emphasised seeing the doctor constantly
6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?		6. Uqiniseke kangakanani ngento yokuba unakho ukwenza izinto ngaphandle kokusebenzisa iyeza ukunciphisa ubungakanani bempembelelo yesigulo sakho kubomi bakho bemihla ngemihla?	6. Uqiniseke kangakanani ngento yokuba unakho ukwenza izinto ngaphandle kokusebenzisa iyeza ukunciphisa ubungakanani bempembelelo yesigulo sakho kubomi bakho bemihla ngemihla?	Synonyms for affect. B's wording is used more commonly and was selected.

Table C-6: Back translation of the SE-6

SE-6 English	SE-6 AB Back translation (Translator C)	SE-6 AB Back translation (Translator D)	Comments
Self-Efficacy for Managing Chronic Disease 6-Item Scale	Your skill in controlling a Disease which does not end – a scale which has 6 Grades/Levels	Your capability in dealing with a chronic illness. In a scale of six levels	Translator C has translated literal meaning, Translator D translated interpretation
We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.	We would like to know how confident you are in doing certain activities / things. In each of the following questions, please select a number which is in line with your confidence in doing the following things / activities.	We would like to know how confident you are in doing certain things. In each of the following questions, please choose a number that best describes your level of confidence in doing certain things.	Regularly at the present time - the tense of the sentence in Xhosa implies the present time, the need to include a term to refer to regularly was discussed and consensus reached
not at all confident	Not confident at all	Not confident at all	
totally confident	Fully confident	Perfectly confident	
1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	How confident are you that you can control tiredness caused by your illness in interfering with things you want to do?	How confident are you that you will be able to deal with the tiredness caused by your illness, which prohibits you from doing things you would like to do?	The need emphasise that interference does not mean total prohibition was raised. Again the issue that in Xhosa culture terms are used as absolutes.
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	How confident are you in preventing body weight or pains caused by your illness in interfering with things you want to do?	How confident are you that you will be able to avoid the bodily suffering or pain caused by your illness which also prohibits you from going on with things you would like to do?	Literal translation to come to the term body weight, consensus was that the meaning verbally would be interpreted as per D.

SE-6 English	SE-6 AB Back translation (Translator C)	SE-6 AB Back translation (Translator D)	Comments
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	How confident are you in preventing spiritual pain caused by your illness in interfering with things you want to do?	How confident are you that you will be able to avoid emotional suffering caused by your illness, which prohibits you from going on with the things you would like to do?	Again that lack of vocabulary for emotional or mood issues highlighted thus the literal translation of spiritual pain but translator D interpreting it as emotional.
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	How confident are you in preventing other symptoms or health problems you have in interfering with things you want to do?	How confident are you that you will be able to avoid other symptoms or health problems you have that may prohibit you from going on with the things you would like to do?	
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	How confident are you in doing necessary activities to control your state of health in order to decrease a need to see a doctor?	How confident are you that you will be able to do the necessary in dealing with the state of your health by minimising having to see a doctor?	
6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?	How confident are you in doing things without medication in decreasing the influence of your illness in your daily life?	How confident are you that you will be able to do the necessary without having to rely on medication and minimising the effects of your illness in your daily life?	

# **Appendix D: Information sheet and informed consent for prevalence study**

## **INFORMATION SHEET**

### **A STUDY INTO HOW LIVING WITH HIV AFFECTS QUALITY OF LIFE**

#### **WHAT ARE WE TRYING TO DO?**

We are researchers from the University of Cape Town and we are interested in finding out in what ways being HIV positive makes a difference to a person's life. We want to answer questions such as: How are people who are HIV positive affected by the disease? Do the symptoms of the disease affect the way in which people play a role in the family and take part in community activities? In order to answer these questions we would like to interview people who are HIV positive.

#### **WHY HAVE WE CONTACTED YOU?**

We are working with the Western Cape Department of Health and as a patient registered with the Michael Mapongwana HIV Clinic you might be interested in taking part in the study.

#### **WHAT WILL YOU BE ASKED TO DO?**

You will be interviewed by someone who has been trained in the use of a questionnaire. This will find out more about how you as a person who is HIV positive cope with the disease, how you look after yourself, how you manage to make a living and what things are difficult to do.

Each interview will take about 45 minutes. We know that this is a long time but we want to get as much information as possible so that we can better understand the problems that you face.

### **WHAT WILL I GET IF I TAKE PART?**

There is no payment or reward for taking part in the study and there is no reason for you to take part unless you would like to help us understand the situation of people living with HIV better. We will make all the information we collect known to the local authorities (but of course *not* your name or address), to the local institutions that provide assistance to people living with HIV/AIDS and to provincial and central government. We hope that what we find might lead to changes being made, but we cannot promise this. In the short term there will be no direct benefit to you or your family.

Nothing bad will happen to you if you do not want to take part. Even if you do take part, you can stop answering questions at any time and you can refuse to answer specific questions. If you would like them to do so, the people interviewing you will refer you to whatever services you need which may be available in the area.

### **WILL PEOPLE KNOW WHAT ANSWERS I HAVE GIVEN?**

All the answers will be put together and no-one will know who gave any specific answer except the researchers and maybe members of the Ethics Committee of the University of Cape Town (which is a committee that makes sure that people who take part in research are protected). Your name will not be given to anyone and will not be listed anywhere. The results of the project will be made available to organizations involved in assisting people living with HIV/AIDS, local and government authorities and the scientific community but no names will be linked to any results.

**Your participation is appreciated. Should you have any questions please contact Romy Parker at the University of Cape Town on (021) 4066571.**

Dear participant

Please read the attached information sheet.

We hope that this research will help health professionals to better understand how being HIV positive affects your life. All questionnaires are anonymous and records will be kept strictly confidential.

You are welcome to contact the Investigator, Romy Parker at (021) 4066571, senior lecturer in Physiotherapy at the University of Cape Town for further details about the research and your rights. This research is voluntary and refusal to participate or decision to withdraw at any time will involve no penalty or loss of benefits to which you, the participant, are otherwise entitled.

I, \_\_\_\_\_ acknowledge that I have read and understand the above information and have willingly chosen to participate in the study. I know that I can withdraw at any time and that I do not have to answer all of the questions if I do not want to.

I give permission for the staff of \_\_\_\_\_ to give my name and address to the researchers. I also give permission for the researchers to contact me to interview me. I agree to attend the clinic to be interviewed and to take part in the study.

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date



# Appendix E: Measurement Instruments

## Demographic Data

Date of Birth: \_\_\_\_\_

HIV status:

Stage 1

Date of diagnosis: \_\_\_\_\_

Stage 2

Stage at diagnosis: \_\_\_\_\_

Stage 3

CD4+ at diagnosis: \_\_\_\_\_

Stage 4

Most recent CD4+: \_\_\_\_\_

(incl. date)

HIV management:

Monitoring

First-line ARVs

Date initiated \_\_\_\_\_

Second-line ARVs

Date initiated \_\_\_\_\_

Current HIV medication:

AZT (Zidovudine)

EFV (Efavirenz)

ddI (Didanosine)

Nelfinavir

3TC (Lamivudine)

Indinavir

d4T (Stavudine)

Ritonavir

Abacavir

Saquinavir

TDF (Tenofovir)

Atazanavir

FTC (Emtricitabine)

Fosamprenavir

NVP (Nevirapine)

lopinavir/ritonavir

Opportunistic Infections:

Tb - pulmonary

Tb - extra-pulmonary

Oral candidiasis

Syphilis

PCP

Human papillomavirus/genital warts

Toxoplasmosis

Molluscum contagiosum

Cryptococcal meningitis

Seborrhea

Genital herpes

Folliculitis

Vaginal candidiasis (thrush)

Pelvic Inflammatory disease

**Co-morbidities and Associated conditions:**

Diabetes

Hypertension

Peripheral neuropathy

Other \_\_\_\_\_

**Medication for Associated conditions and Opportunistic infections:**

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**Occupation:**

<input type="checkbox"/>	Self employed	<input type="checkbox"/>	Unemployed
<input type="checkbox"/>	In formal employment	<input type="checkbox"/>	Retired
<input type="checkbox"/>	Homemaker/domestic worker	<input type="checkbox"/>	Learner/student
<input type="checkbox"/>	Unemployed - DG	<input type="checkbox"/>	Presently working or ever worked in health services or social welfare
<input type="checkbox"/>	Unemployed - seeking work	<input type="checkbox"/>	Other _____

**Marital Status:**

<input type="checkbox"/>	Single	<input type="checkbox"/>	Widowed
<input type="checkbox"/>	Married	<input type="checkbox"/>	Separated
<input type="checkbox"/>	Partner	<input type="checkbox"/>	Divorced

**Languages:**

<input type="checkbox"/>	IsiXhosa	S = Spoken language
<input type="checkbox"/>	English	W = Spoken and written language
<input type="checkbox"/>	Afrikaans	
<input type="checkbox"/>	IsiZulu	
<input type="checkbox"/>	Other _____	

**Dependents (list number):**

<input type="checkbox"/>	Children < 16y	_____
<input type="checkbox"/>	Children > 16y	_____
<input type="checkbox"/>	Partner/spouse	_____
<input type="checkbox"/>	Parent/s	_____
<input type="checkbox"/>	Siblings	_____
<input type="checkbox"/>	Other	_____

**Education:**

<input type="checkbox"/>	Attended school
_____	Highest grade achieved at school
<input type="checkbox"/>	Diploma or equivalent

**Smoking:**

<input type="checkbox"/>	Currently Smoke	Cigarettes per day: _____
<input type="checkbox"/>	Have smoked	Years smoked: _____
<input type="checkbox"/>	Never smoked	

**Alcohol:**

<input type="checkbox"/>	Current
	Units/week: _____
<input type="checkbox"/>	Past
	Units/week: _____

<b>Units:</b>
Quart of beer = 3.7    Can of beer = 1.5
250ml of wine = 3    Bottle of wine = 9
330ml cider = 2
Spirits shot (gin, brandy, whiskey) = 1.5

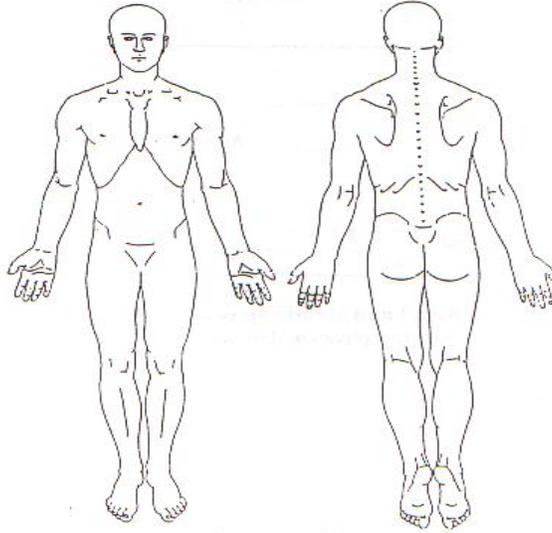
# BRIEF PAIN INVENTORY

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

Have you had pain other than these everyday kinds of pain during the last week?

Yes No

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



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

0 1 2 3 4 5 6 7 8 9 10  
 No Pain Pain as bad as you can imagine

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

0 1 2 3 4 5 6 7 8 9 10  
 No Pain Pain as bad as you can imagine

5. Please rate your pain by circling the one number that best describes your pain on the **average**.

0 1 2 3 4 5 6 7 8 9 10  
 No Pain Pain as bad as you can imagine

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

0 1 2 3 4 5 6 7 8 9 10  
 No Pain Pain as bad as you can imagine

7. What treatments or medications are you receiving for your pain?

---

8. In the last week, how much **relief** have pain treatments or medications provided? Please circle the one percentage that most shows how much *relief* you have received.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
No										Complete
Relief										Relief

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

**A. General Activity**

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

**B. Mood**

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

**C. Walking Ability**

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

**D. Normal Work** (includes both work outside the home and housework)

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

**E. Relations with other people**

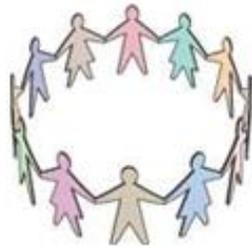
0	1	2	3	4	5	6	7	8	9	10
Does not										Completely
interfere										interferes

**F. Sleep**

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

**G. Enjoyment of life**

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



## Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?  
Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?  
Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?  
Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?  
Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?  
Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident
6. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your every day life?  
Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

### Scoring:

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the scale is the mean of the six items. If more than two items are missing, do not score the scale. Higher number indicates higher self-efficacy.

# **EQ - 5D**

**Health Questionnaire**

South African English version

By placing a tick in one box in each group below, please indicate which statements best describe your own state of health TODAY.

**Mobility**

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

**Self-Care**

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

**Usual Activities** (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

**Pain/Discomfort**

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

**Anxiety/Depression**

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

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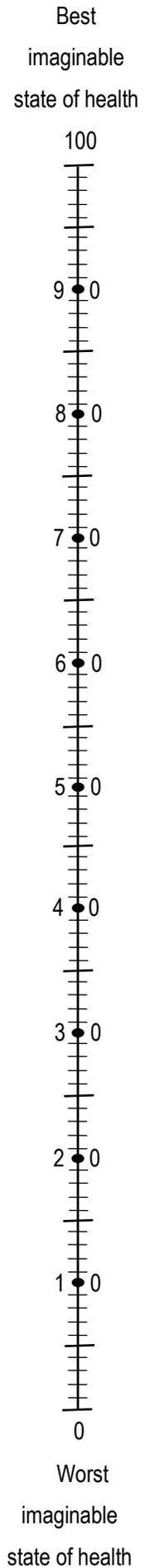
Compared with my general level of health over the past 12 months, my state of health today is:

- Better  PLEASE TICK
- Much the same  ONE
- Worse  BOX

To help people say how good or bad their state of health is, we have drawn a scale on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale, in your opinion, how good or bad your own health is today. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your state of health is today.

**Your own  
state of health  
today**



**Childhood Trauma Questionnaire – Short Form (CTQ-SF)**  
**Copyright 1996 David P. Bernstein, Ph.D., Laura Fink, Ph.D.**

**Instructions:** These questions ask about some of your experiences growing up as a child and a teenager. For each question, circle the number that best describes how you feel. Although some of these questions are of a personal nature, please try to answer as honestly as you can. Your answers will be kept confidential.

	Never	Rarely	Sometimes True	Often	Very
When I was growing up, ...					
1. I didn't have enough to eat.	1	2	3	4	5
2. I knew there was someone to take care of me and protect me	1	2	3	4	5
3. People in my family called me things like "stupid", "lazy", or "ugly".	1	2	3	4	5
4. My parents were too drunk or high to take care of me.	1	2	3	4	5
5. There was someone in my family who helped me feel important or special.	1	2	3	4	5
6. I had to wear dirty clothes.	1	2	3	4	5
7. I felt loved.	1	2	3	4	5
8. I thought that my parents wished I had never been born.	1	2	3	4	5
9. I got hit so hard by someone in my family that I had to see a doctor or go to the hospital.	1	2	3	4	5
10. There was nothing I wanted to change about my family.	1	2	3	4	5
11. People in my family hit me so hard that it left bruises or marks.	1	2	3	4	5
12. I was punished with a belt, a board, a cord, or some hard object.	1	2	3	4	5
13. People in my family looked out for each other.	1	2	3	4	5
14. People in my family said hurtful or insulting things to me.	1	2	3	4	5
15. I believe that I was physically abused.	1	2	3	4	5
16. I had the perfect childhood.	1	2	3	4	5
17. I got hit or beaten so badly that it was noticed by someone like a teacher, neighbour, or doctor.	1	2	3	4	5
18. I felt that someone in my family hated me.	1	2	3	4	5
19. People in my family felt close to each other.	1	2	3	4	5
20. Someone tried to touch me in a sexual way, or tried to make me touch them.	1	2	3	4	5
21. Someone threatened to hurt me or tell lies about me unless I did something sexual with them.	1	2	3	4	5
22. I had the best family in the world.	1	2	3	4	5
23. Someone tried to make me do sexual things or make me watch sexual things.	1	2	3	4	5
24. Someone molested me.	1	2	3	4	5
25. I believe that I was emotionally abused.	1	2	3	4	5
26. There was someone to take me to the doctor if I needed it.	1	2	3	4	5
27. I believe that I was sexually abused	1	2	3	4	5
28. My family was a source of strength and support.	1	2	3	4	5

## Beck's depression inventory

In this questionnaire there are groups of statements. Please read each group carefully. Thereafter from the set choose one answer that describes best your feeling DURING THE PAST WEEK INCLUDING TODAY. Encircle the number of the answer you choose. If there are answers that are of equal importance encircle each one of them. Before making your choice make sure that you have read the statements thoroughly.

- |   |  |
|---|--|
| <p>1. I do not feel sad. 0<br/>           I feel sad. 1<br/>           I am always sad and cannot change from this situation. 2<br/>           I am very sad and it makes me unhappy that I cannot stand this. 3</p>  | <p>8. I do not feel different (odd) from another person. 0<br/>           I blame myself for my weaknesses or mistakes. 1<br/>           I regret all the time about my mistakes. 2<br/>           I regret all the time the bad thing that is happening. 3</p>                        |
| <p>2. I have not as yet been discouraged by a matter that pertains to the future. 0<br/>           I feel discouraged by certain factors that pertain to the future. 1<br/>           I do not feel like doing anything in life. 2<br/>           I do not feel any hope for my future and nothing can change that. 3</p> | <p>9. I have no thoughts of committing suicide at all. 0<br/>           I sometimes think of committing suicide but never do it. 1<br/>           I would like to commit suicide. 2<br/>           I can commit suicide if I can get a chance. 3</p>                                   |
| <p>3. I do not feel like a person who is unsuccessful. 0<br/>           I feel I am the most unsuccessful person for a person of my age. 1<br/>           When I look back in my life I only see failure. 2<br/>           I feel I am a complete failure. 3</p>  | <p>10. I no longer cry as I used to. 0<br/>           I cry now a lot than I used to. 1<br/>           I cry all the time. 2<br/>           I used to be able to cry but I am now unable even when I want to. 3</p>  |
| <p>4. I find a lot of satisfaction in many things as usual. 0<br/>           I do not enjoy things in the usual manner. 1<br/>           I no longer get enough satisfaction in anything. 2<br/>           I am not satisfied and I am tired of everything. 3</p>   | <p>11. I no longer get upset that much as I used to in the past. 0<br/>           I get upset quickly and easily than before. 1<br/>           I now feel upset all the time. 2<br/>           I no longer get fully upset by what used to upset me before. 3</p>                      |
| <p>5. I do not feel guilty. 0<br/>           I feel guilty most of the time. 1<br/>           I feel guilty a great deal of the time. 2<br/>           I feel guilty all the time. 3</p>  | <p>12. I have not yet lost interest in other people. 0<br/>           I do not have a lot of interest in other people than before. 1<br/>           I lost a lot of interest in other people. 2<br/>           I lost interest completely in other people. 3</p>                       |
| <p>6. I do not feel punished. 0<br/>           I feel I being punished. 1<br/>           I had expected to be punished. 2<br/>           I feel punished. 3</p>   | <p>13. I still make a decision as I did before. 0<br/>           I postpone decision making more than I used to. 1<br/>           I experience great difficulty in making decisions than before. 2<br/>           I no longer know how to take decisions fully. 3</p>                  |
| <p>7. I do not feel ashamed of being who I am. 0<br/>           I feel ashamed of being who I am. 1<br/>           I hate myself. 2<br/>           I detest myself. 3</p>   | <p>14. I do not find myself odd than usual. 0<br/>           I get worried over the fact that I look old or attractive to people. 1<br/>           I feel there are permanent changes in my appearance that cause me not to be attractive. 2<br/>           I believe I am ugly. 3</p> |

## Beck's depression inventory

In this questionnaire there are groups of statements. Please read each group carefully. Thereafter from the set choose one answer that describes best your feeling DURING THE PAST WEEK INCLUDING TODAY. Encircle the number of the answer you choose. If there are answers that are of equal importance encircle each one of them. Before making your choice make sure that you have read the statements thoroughly.

- |   |  |
|---|--|
| <p>15. I can work on anything like before. 0<br/>           It takes a lot of effort to start doing something. 1<br/>           In order to start doing something I must force myself. 2<br/>           I cannot do any work at all. 3</p> <p>16. I can no longer sleep in the usual way. 0<br/>           I do not sleep in the usual way. 1<br/>           I wake up an hour to two before the time and it becomes difficult to sleep again. 2<br/>           I wake up a few hours before the usual time and it becomes difficult to sleep again. 3</p> <p>17. I do not get more tired than usual. 0<br/>           I get tired quickly and easily than usual. 1<br/>           I get tired with almost everything I do. 2<br/>           I am too tired to do anything. 3</p> <p>18. My appetite for food is not above normal. 0<br/>           My appetite for food is not normal. 1<br/>           My appetite for food is much worse now. 2<br/>           I have completely lost appetite for food. 3</p> | <p>19. I have lost weight lately, if there is any. 0<br/>           I have lost over 5 kilograms. 1<br/>           I have lost over 10 kilograms. 2<br/>           I have lost over 15 kilograms. 3<br/>           I am trying to lose weight deliberately by eating less. 0</p> <p style="text-align: right;">Yes / No</p> <p>20. I no longer worry more than is normal about my health. 0<br/>           I now worry about physical problems like pains or an upset or windy stomach. 1<br/>           I am very worried about bodily problems and it is difficult to think about other things. 2<br/>           I am so worried about the problems of my body that I cannot think of something else. 3</p> <p>21. I have not noticed any change in my sexual interest. 0<br/>           I have less interest in sex. 1<br/>           I have now very little interest in sex. 2<br/>           I have lost all interest in sex. 3</p> |
|---|--|

Listed below are a number of difficult or stressful events that sometimes happen to people. For each **event** tick (✓) **one or more of the boxes** to the right to indicate that a) it happened to you, b) you witnessed it happen to someone else, c) you heard about it happening to someone you know

**LIFE EVENTS QUESTIONNAIRE\***

	Happened to me	Witnessed it	Heard about it
1. Natural disaster (such as a flood, earthquake or severe drought)			
2. Fire or explosion			
3. Life-threatening transport accident (taxi, train, car, plane or boat)			
4. Serious accident at work, home or when playing sports or having fun			
5. Physical assault (being attacked, beaten, slapped, kicked)			
6. Assaulted with a weapon (being shot, stabbed, threatened with a knife, gun or bomb)			
7. Sexual assault (rape, attempted rape, forced to perform sexual acts or threats of harm)			
8. Other unwanted or uncomfortable sexual experience			
9. Exposure in a war-zone (in combat or as civilian)			
10. Captivity (being kidnapped, abducted, held hostage or prisoner of war)			
11. Life-threatening illness or injury			
13. Exposed to sudden or violent death (murder or suicide)			
14. Sudden, unexpected death of someone close to you			
15. Serious injury, harm or death you caused to someone else			
16. As a child - badly beaten by your parents or the people who raised you			
17. Badly beaten by a spouse (husband/wife) or a partner			
18. Another life-threatening experience not mentioned here			

**IF YOU HAD TICKED YES (✓) TO MORE THAN ONE TRAUMA, PLEASE SELECT THE ONE THAT HAS AFFECTED YOU THE MOST AND WRITE IT DOWN HERE:**

.....  
 .....

**NOW PLEASE COMPLETE THE NEXT QUESTIONNAIRE.**

## THE HTS

From the events you have marked above, think of the one that was **MOST UPSETTING** to you  
**Please specify the event that you feel is most upsetting and still bothering you:**

Below are the following symptoms that people sometimes experience after traumatic experiences. Please read each one carefully and decide how much the symptoms bothered you during the **past week** :

	Not at all	A Little	Quite a bit	Extremely
H1. Thoughts or memories that keep coming back of that event/s you specified				
H2. Feeling as though the event is happening again				
H3. Nightmares about the event/s that keep coming back				
H4. Feeling detached or withdrawn from people				
H5. Unable to feel emotions				
H6. Feeling jumpy, easily startled				
H7. Difficulty concentrating (focus your mind on tasks)				
H8. Trouble sleeping				
H9. Feeling on guard (mistrusting others)				
H10. Having outbursts of anger				
H11. Avoiding activities that remind you of the traumatic or hurtful event.				
H12. Inability to remember parts of the most traumatic or hurtful events.				
H13. Feeling less interested in daily activities				
H14. Feeling as if you don't have a future				
H15. Avoiding thoughts and feelings associated with the traumatic or hurtful events				
H16. Sudden emotional or physical reaction when reminded of the most hurtful part of the traumatic event.				
H17. Feeling that people do not understand what is happening to you				
H18. Having difficulty doing your job or daily tasks because of what happened to you				
H19. Blaming yourself for things that have happened				
H20. Feeling guilty for having survived				
H21. Feeling there is no hope				
H22. Feeling ashamed of the hurtful or traumatic event that happened to you				
H23. Feeling as if you are going crazy.				
H24. Spending time thinking why these events happened to you				
H25. Feeling that you are the only one who suffered these events				
H26. Feeling others are hostile or want to harm you				
H27. Feeling that you have no-one to rely on				
H28. Finding out or being told by other people that you have done something that you cannot remember				
H29. Feeling as if you are split into two people and one of you is watching what the other one is doing				
H30. Feeling someone you trusted betrayed you				



## Appendix F: Additional data from prevalence study

Table F-1: Frequency table of ART

	Count	Percentage (%)
3TC/EFV	2	0.9
3TC/ <b>d4T</b> /NVP	23	10.0
3TC/NVP	2	0.9
3TC/TDF/LPV/r	10	4.4
3TC/ <b>d4T</b> /EFV	30	13.1
3TC/TDF/NVP	13	5.7
3TC/AZT/NVP	1	0.4
3TC/LPV/r/TNF	1	0.4
3TC/TDF/EFV	15	6.6
AZT/3TC/NVP	47	20.5
AZT/3TC/EFV	23	10.0
AZT/ <b>ddI</b> /3TC	1	0.4
AZT/ <b>ddI</b> /LPV/r	12	5.2
AZT/3TC/LPV/r	1	0.4
AZT only (pregnant)	5	2.2
Defaulted	4	1.8
unknown	1	0.4
Missing	39	17

Note: drugs known to be associated with painful peripheral neuropathy in **bold**

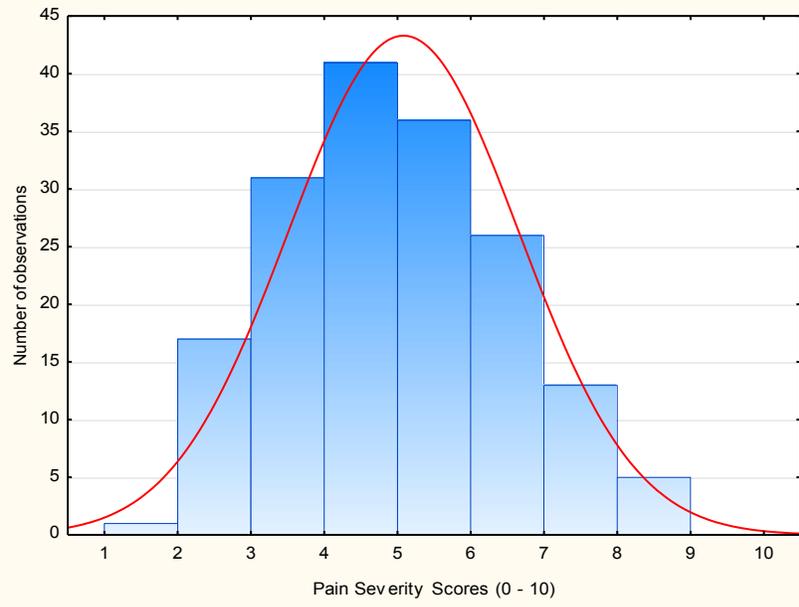
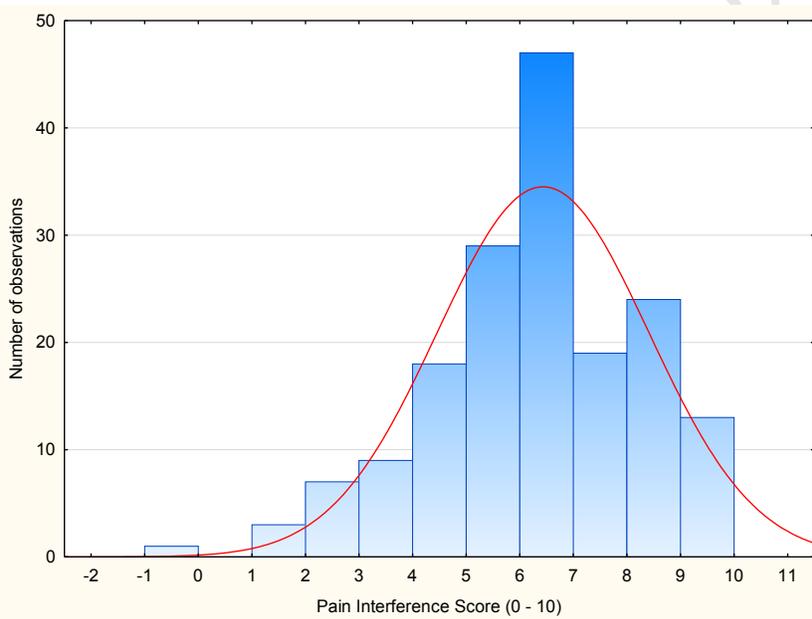


Figure F-1: Distribution of responses for Pain Severity Scores (PSS)



*Note that responses show between 0 and -1 indicate scores of 0*

Figure F-2: Distribution of responses for pain Interference Scores (PIS)

Table F-2: Health related quality of life as reported on EQ-5D-Xhosa

	<b>Sample (N = 229)</b>	<b>Pain group (n = 170)</b>	<b>Pain Free Group (n = 59)</b>	
	Number (%)	Number (%)	Number (%)	Significance Test
<b>Mobility</b>				$\chi^2= 11.39; p = 0.001$
No problems	188 (82.10)	131 (77.06)	57 (96.61)	
Some problems	41 (17.90)	39 (22.94)	2 (3.39)	
Confined to bed	0	0	0	
<b>Self-care</b>				$\chi^2= 2.35; p = 0.125$
No problems	216 (94.32)	158 (92.94)	58 (98.31)	
Some problems	13 (5.68)	12 (7.06)	1 (1.69)	
Unable to wash or dress self	0	0	0	
<b>Usual activities</b>				$\chi^2= 16.82; p < 0.001$
No problems	189 (82.53)	130 (76.47)	59 (100)	
Some problems	37 (16.16)	37 (21.76)	0	
Unable to perform	3 (1.31)	3 (1.76)	0	
<b>Pain/Discomfort</b>				$\chi^2= 80.09; p < 0.001$
No pain or discomfort	75 (32.75)	28 (16.47)	47 (79.66)	
Moderate pain or discomfort	135 (58.95)	123 (72.35)	12 (20.34)	
Extreme pain or discomfort	19 (8.30)	19 (11.18)	0	
<b>Anxiety/Depression</b>				$\chi^2 = 15.47; p < 0.001$
Not anxious or depressed	143 (62.45)	94 (55.29)	49 (83.05)	
Moderately anxious or depressed	73 (31.88)	63 (37.06)	10 (16.95)	
Extremely anxious or depressed	13 (5.68)	13 (7.65)	0	

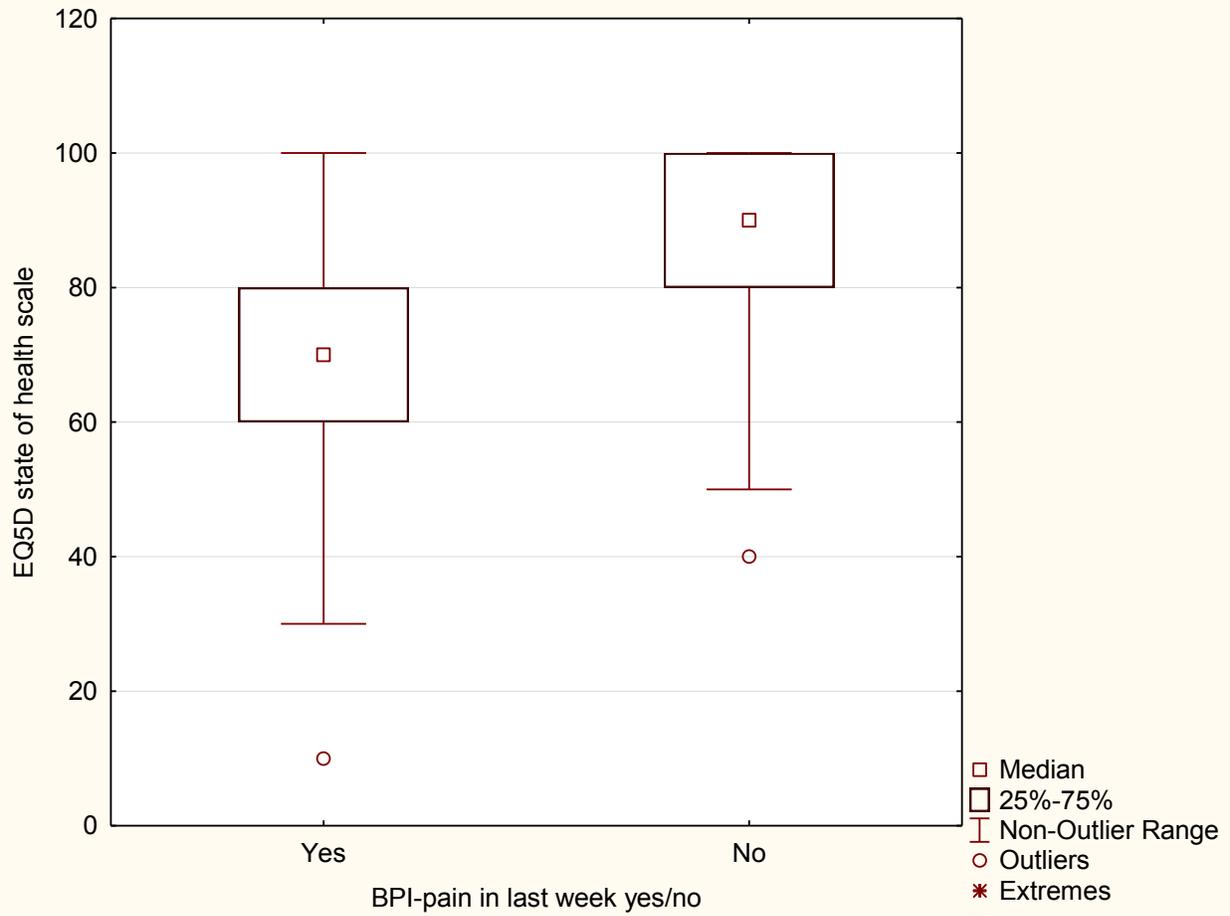


Figure F-3: Box and whisker plot of EQ VAS scores by group

Table F-3: Categorical analysis of responses on the Childhood Trauma Questionnaire - Xhosa

	Sample (n = 173)	Pain group (n = 133)	Pain Free Group (n = 40)	
	Count (%)	Count (%)	Count (%)	Significance Test
<b>Emotional Neglect</b>				$\chi^2 = 4.87$ ; p = 0.182
None or Minimal	131 (75.72)	98 (73.68)	33 (82.50)	
Low to Moderate	33 (19.08)	33 (20.30)	6 (15.00)	
Moderate to Severe	7 (4.05)	7 (4.51)	1 (2.50)	
Severe to Extreme	2 (1.16)	2 (1.50)	0 (0)	
<b>Emotional Abuse</b>				$\chi^2 = 5.86$ ; p = 0.119
None or Minimal	89 (51.45)	68 (51.13)	21 (52.50)	
Low to Moderate	62 (35.84)	46 (34.59)	16 (40.00)	
Moderate to Severe	13 (7.51)	11 (8.27)	2 (5.00)	
Severe to Extreme	9 (5.20)	8 (6.02)	1 (2.50)	
<b>Physical Abuse</b>				$\chi^2 = 0.31$ ; p = 0.959
None or Minimal	124 (71.68)	96 (72.18)	28 (70.00)	
Low to Moderate	14 (8.09)	11 (8.27)	3 (7.50)	
Moderate to Severe	14 (8.09)	11 (8.27)	3 (7.50)	
Severe to Extreme	21 (12.14)	15 (11.28)	6 (15.00)	
<b>Sexual Abuse</b>				$\chi^2 = 2.18$ ; p = 0.536
None or Minimal	121 (69.94)	90 (67.68)	31 (77.50)	
Low to Moderate	15 (8.67)	13 (9.77)	2 (5.00)	
Moderate to Severe	21 (12.14)	16 (12.03)	5 (12.50)	
Severe to Extreme	16 (9.25)	14 (10.53)	2 (5.00)	



## Appendix G: Positive Living Workbook

### Positive Living

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Name: \_\_\_\_\_

# Positive Living

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Welcome to “Positive Living”. This is a workbook designed to be used over 6 weeks which aims to help people develop self-management skills for living with HIV/AIDS. Using this workbook is not about sitting and reading or listening. In order to get the most out of this course you will be asked to share your experiences, you will need to set goals and share those goals with others and you will need to take part in activities. This workbook is NOT a substitute for any other medical care that has been recommended for the treatment of your condition.

You will benefit most from this workbook if you commit yourself to completing all the sessions within a 6 week period of time. Scientific research tells us that these courses are of great benefit to people living with chronic diseases such as diabetes, arthritis and HIV/AIDS. But to benefit from the course, using the workbook regularly over 6 weeks and participating in activities is essential. The workbook is divided into six sections:

1. Week 1: Self-management and Exercise
2. Week 2: Managing common symptoms of HIV/AIDS
3. Week 3: Stress Management
4. Week 4: Pain
5. Week 5: Eating Well
6. Week 6: Continuing as a successful self-manager

Your course leader is \_\_\_\_\_. She has been trained in all the information you will be going through. She has also been trained by a physiotherapist who specializes in HIV/AIDS in safe ways to exercise and in relaxation techniques.

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## Week 1: Self-Management and Exercise

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What do we mean by the term “self-management”? Self-management does not mean that you are expected to look after your health on your own with no help. No, someone who is a successful self-manager takes responsibility for their health. This means that they choose to work with the health team, with their drugs and with themselves to live a healthy life (just like a manager in a business – they don’t do everything themselves, they work with a team).

There are lots of things you can learn to do which will help you to be a successful self-manager. First of all it is important to understand HIV and AIDS. You need to understand about the virus and the disease, how it is transmitted, how it can affect you and about the medications used to treat it.

The next step in being a self-manager is being able to think about this information in terms of how it affects you. The final step in being a self-manager is to think about what it is that you want to be able to do, decide how you are going to do it and then to learn and practice the skills you need to be able to do it. Some of the things you will learn about and practice every day when you do this course include exercising, relaxation techniques and healthy eating.

Using this workbook you will learn about exercise and its benefits, in the second section you will learn a bit about the common symptoms of HIV/AIDS and how to manage these. The third section will focus on stress management, the final sections focus on pain, and eating well. Some people using this workbook may already know a lot about these topics, others may not know very much. It is important to share information and make sure that everyone has the knowledge they need to become a self-manager, even if you think you know a lot about these topics it is still worth your going through the workbook to make sure you have not missed out on any information. Scientific research tells us that people who are well informed about their health manage better and have a better quality of life. Using this workbook, you will also learn about and discuss the steps that are needed to become a good self-manager. Let’s look at these steps here.

## Self-management steps

### Step 1:

To be good at self-management you need to learn and practice several skills which you will practice through this course. The first step is to decide *what* it is you want to be able to do. This can be the hardest step to think about. For example you might be feeling very sad and depressed. First you need to think about why you are feeling that way. Perhaps one of the reasons you are feeling that way is that you have lost touch with your friends. Your first step might be to decide that you need to meet people to make friends. This will help you to feel less sad and depressed.

Write down here three things that you want to be able to do:

1) \_\_\_\_\_  
\_\_\_\_\_

2) \_\_\_\_\_  
\_\_\_\_\_

3) \_\_\_\_\_  
\_\_\_\_\_



### Step 2:

But deciding that you are going to meet people and make friends doesn't mean it will happen. You have to make it happen. The second step in being a self-manager is to decide *how* you are going to do it. Sometimes the thought of doing something new can seem too much and we don't even try. If you want to meet people to make friends you need to think about all the different options you have to do this. For example you could invite your neighbours for tea, or you could decide you would meet people by going to church, by joining a support group or an exercise group. Never assume that what you want to be able to do is impossible. Always look for every option and look at it from every angle.

Write down here three different ways that you could try to achieve what you want to do:

1) \_\_\_\_\_

2) \_\_\_\_\_

3) \_\_\_\_\_



Now that you have decided on *how* you can try to achieve what you *want*, you need to make an action plan. It is important that this plan is realistic otherwise it is likely you will not succeed. How do you do this?

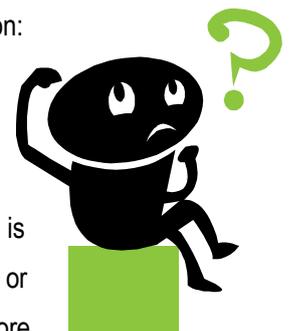
- First decide what you are going to do *this week*
- Now make a *specific plan*

Saying that this week I'm going to try to meet some people is NOT a specific plan. To be specific, the plan must have different parts. It is useful to ask yourself some questions to help develop a specific plan. Questions like:

- *What?*  
Exactly what are you going to do? For example you could decide that to meet people you are going to invite your neighbour for tea.
- *How much?*  
Then you must decide how much you are going to do. For example are you going to invite one neighbour for tea or are you going to invite lots of neighbours over. Lots of people are much more tiring than one person. Or do you want to invite your neighbour for lunch? But lunch means a lot more preparation and time and will make you more tired. So you have to decide how much you can do.
- *When will you do it?*  
Then you must decide on exactly which day you are going to do the activity and at what time of the day. Maybe it is better to invite your neighbour for tea in the morning because you get tired in the afternoon. Or if you feel sick in the morning from your medicines maybe it is better to invite your neighbour for afternoon tea. Or maybe your neighbour works and you need to invite them for tea at the weekend.
- *How often?*  
This is always the hardest part. We all would like to be able to do more things every day. But we are human and this is not always possible. When people want to start exercising, we often say we are going to do it every day. But this is often just not possible and if we then miss a day we feel that we have failed and we give up. How often will you invite your neighbour for tea? Not every day but maybe once a week. You know that you won't become friends immediately and that it will take time.
- *Is it a good plan?*

To test whether you have come up with a good plan you need to ask yourself this question:  
*"If I give myself a score from 0 -10 for how confident I am that I will achieve my plan this week, where 0 is not at all confident, and 10 is totally confident. What score will I give to show how confident I am that I can complete this plan?"*

If your answer is 7 or more out of 10 then this is probably a very good plan. If your score is less than 7 you need to think about why you are not confident. What are the problems or barriers? Can you change the plan or solve the problems to make yourself feel more confident?



### Step 3:

Now, write your plan down and put it somewhere you will see it every day. There is an action plan form at the end of this section and 5 more at the back of this book. Use them every week you are doing this course. You can always draw more of them to keep working on your plans in the future.

#### **A good action plan is:**

- Something I want to do
- Something I can expect to do this week
- Is specific
- Answers the questions: What? How much? When? How often?
- I am confident that I can achieve with a score of at least 7 out of 10.

Now you need to carry out your action plan. If it is a good plan then doing it is usually fairly easy. It helps to tell family or friends what your plan is and to report back to them on how you are doing. On this course you are going to make a plan every week and record how you get on. It helps to report back on things because you can then have an idea on how well you are doing. If you haven't been able to keep to the plan you can discuss the problems you might have had and make plans to cope with them.

### Step 4:

Always check your results and give yourself a reward for having achieved your plan. Also think about how achieving your plan is making you feel. In the example we talked about, you could congratulate yourself for having invited your neighbour for tea, you would also think about how you now feel. Is the plan helping you to achieve what you want?



### What about problems?

What if your plan doesn't work? Are you going to give up and decide you had a bad plan? There are seven steps to solving problems. These are:

1. Deciding what the problem is (you might need friends and family to help here)
2. List ideas to solve the problem
3. Select one idea to try
4. How did it go?
5. If it didn't work, try another idea
6. If your ideas don't work, ask friends, family, counsellors, professionals for ideas
7. Finally you might have to accept that you can't solve the problem now.

### **A successful self-manager is someone who:**

- Sets goals
- Makes a list of ways to achieve those goals
- Makes action plans to achieve the goals
- Carries out the action plans
- Checks on their progress every week
- Can change the action plan if there are problems
- Gives themselves a reward for achieving their goals

At the end of each section and at the back of the workbook there are “Action Plan Forms”. Use these forms to plan what you want to do and how you are going to do it. We are now going to discuss exercise – use the “Action Plan Form” at the end of this section to plan what exercise you are going to do this week.



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# Exercise

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Exercise is a very important way to keep healthy. Scientific research tells us that exercise has a lot of good effects on our bodies like helping our digestive system absorb and process food; it trains our hearts so that they are strong and healthy and keeps our lungs working well. Exercise makes our muscles and bones strong and our joints flexible so that we can keep moving. Exercise also helps to make us feel happy, improves concentration and memory, improves sleep and exercise helps to decrease the chances of developing chronic illnesses like high blood pressure and cancers.



In the past, when people became ill with a chronic illness like high blood pressure or diabetes or HIV/AIDS, medical care focused on helping them when their symptoms became worse. Treatment focused on using drugs and people were often advised to rest or decrease their activity. Today we know that if we teach people who develop chronic illnesses about their disease and encourage them to do exercise we can prevent a lot of the problems which used to be treated with medicines. We also know that exercise can help to treat a lot of the symptoms which people with chronic diseases develop. Symptoms which may be caused by the disease or by the drugs used to treat the disease.

You may be wondering if it is safe for you to exercise when you have an illness like HIV/AIDS. Research tells us that **it is safe for people living with HIV/AIDS to do exercise**. Not only is it safe, it also stimulates the immune system, improves endurance and decreases fatigue, improves strength and decreases body fat. We also know that strengthening exercises seem to help prevent or decrease lipodystrophy in people who are taking ARVs (Lipodystrophy means that your body stops storing fat in places where it normally stored it - like in your buttocks, and begins to store the fat in places like your chest or your stomach). We know that people who are physically fit get fewer colds and take fewer days off work because of illness. One of the biggest benefits of exercise is that exercising regularly makes you feel more in control of your life.

Although exercise is good for you and safe for you to do, sometimes your body will give you clues that you need to cancel your exercise. If you have a fever, feel dizzy, have vomiting or diarrhoea, if your joints have suddenly become swollen, or if you have a pain which is new and you are not sure what is causing it, it is better to miss an exercise session until you can speak to a nurse or doctor.



### **Exercise is good for:**

- Improving mood
- Strength
- Improving sleep
- Concentration and memory
- Heart and lung health
- Decreasing body fat
- Digestion
- Increasing confidence to self-manage chronic illness.



### **Do not exercise if:**

- You have a fever
- You are dizzy
- You have been vomiting
- You have diarrhoea
- Your joints have suddenly become swollen
- You have a new pain which you don't know the cause of

Miss one exercise session if you have one of these problems until you can speak to a nurse or doctor. This does not mean you should never exercise but you need to make sure you are not becoming ill.

### What kind of exercise should you do?

You do not have to join a gym or a club to get exercise. There are lots of ways of exercising from formal sports like running, playing football or netball, swimming or playing tennis. But, walking is also a very good way to exercise. Any activity which makes your heart beat faster and makes you breathe a little harder is exercise. Dancing is exercise, walking up the stairs is exercise, gardening is exercise. There are lots of ways that we can exercise every day without having to go to a class or join a club. You could walk a little further before catching the bus or the taxi or you could play with your children!

There are three general kinds of exercise you can do. Endurance exercise; like walking, running, dancing or swimming. Endurance exercise is sometimes called aerobic exercise which means that you will be breathing faster and your heart will be beating faster too. We know that this kind of exercise is very important to keep healthy and we need to do 30 minutes of this kind of exercise three times a week to keep healthy. The second kind of exercise is strengthening exercise. This kind of exercise focuses on making us stronger. To make muscles stronger we have to do exercises which make the muscles work hard against a resistance, like weight training but you can also do strength training by working with heavy bags of shopping! The last kind of exercise is stretching exercise. Stretching exercises focus on keeping us mobile and flexible.

#### **Types of exercise:**

- Endurance exercise which makes you breathe harder (sometimes called aerobic)
- Strengthening exercise which makes you stronger
- Stretching or flexibility exercise which makes you more mobile and supple



*Endurance*



*Strengthening*



*Flexibility*

There is an extra reason for people living with HIV/AIDS to do strengthening exercise. Scientific research tells us that strengthening exercises seem to help to prevent or limit lipodystrophy. Lipodystrophy means that your body stops storing fat in places where it normally stored it (like in your buttocks) and begins to store the fat in places like your chest or your stomach. Lipodystrophy doesn't just change the shape of the body, we also know that people who develop lipodystrophy tend to have high cholesterol and low insulin meaning that there is a bigger chance that they will have heart problems or develop diabetes. The exact cause of lipodystrophy is not clear but it seems to occur with certain HIV drugs, in older people and in people with a low T cell count who have been HIV+ for a long time. The most recent research tells us that if you do weight training (which builds up more muscle) you can limit lipodystrophy. This is a very good reason to make sure you do strengthening exercises in your exercise routine.

We know one of the hardest things about exercise is not doing it once, but doing it again and again. There are several steps we can follow to make sure that when we start to exercise we stick to it. We all make lots of excuses why we can't exercise. Let's look at the most common excuses.

#### *"I don't have time"*

It doesn't take a lot of time to start exercising. Five minutes a day is a good start. We make time to take medicine because we know without it we would become ill. Exercise is as important as medicine to help us remain healthy (remember it can never replace your drugs). If we know that it is that important we can make time for it.



#### *"I'm too tired"*

When people become ill they often become less active. As you become less active, your body loses fitness and you become weaker, you may feel stiffer and you tire more easily. This means that exercising might feel harder and so you exercise less. This often results in a downward spiral of activity and people often get to the point where even walking down the street to visit the neighbour can feel like too much. Being active or doing exercise when you are feeling tired will give you more energy and make you feel less tired.



#### *"I'm too sick"*

You may be too sick to undertake very vigorous exercise but you can still aim to be more active. You can even break your exercise into one minute sessions which you repeat several times through your day. The fitter you get, the better you will be able to cope with your illness



### *“I get enough exercise already”*

You may be getting a lot of exercise already in your job or simply walking around doing your daily chores. But for most people if we add this time up, it still isn't enough exercise to keep them fully fit. This kind of exercise also doesn't include one of the most important components that make exercise good for us – fun!



### *“Exercise is boring”*



You don't have to do the exercises that everyone else does if they are boring. Choose something that is fun, exercise with a friend or with your favourite music or listen to the radio. You can also keep your exercises fun by changing them regularly.

### *“Exercise is painful”*

Exercise may be uncomfortable but it shouldn't be painful. If you have pain before you start to exercise, it should not get worse while you are exercising. If you do not have pain before you start to exercise and you start to feel pain while you exercise you need to stop exercising and evaluate your pain using the guidelines in Week 4: Pain. If you have muscle or joint pain for more than two hours after you exercise then you have probably done too much. Next time do a little less, either exercise for less time or less vigorously.

### *“It's too dangerous, it's too hot, it's too cold”*

There are always reasons like this not to exercise. Remember that exercise can be done anywhere and anytime. You can put on music in your home and dance; if it's too hot you could walk around shops which have air-conditioning. Finding a group of people to exercise with will not only make it safer but also more fun!



### *“I know I won't stick to it so there is no point in starting”*



First review the steps we discussed on how to be a successful self-manager. If you set your exercise goals using these steps you have more chance of sticking to your exercises. Remember too the important step of rewarding yourself for achieving your goals, this makes it easier to move on to your next goal. We are now going to have a look at the important steps to take to be successful at putting your exercise plan into action.

### **Steps to success with exercise:**

- Set a clear goal using the steps outlined in “How to be a successful self-manager”
- Choose exercise or activity that you want to do and that is fun
- Set a specific time and place to do your exercise
- Decide how long you are going to stick to the plan before you think about changing it (6 to 8 weeks is a good time to work on things)
- Keep an exercise diary to keep track of how you are doing (there is one at the back of this booklet for you to use)
- Keep track of your progress using the exercise diaries in this workbook.
- Start – don’t wait, start now. Begin gradually and proceed slowly
- Revise your programme. At the end of the 6 – 8 weeks make a new plan for the next 6 weeks
- Reward yourself. It is a reward to feel better and healthier but also give yourself a reward for achieving your goal, like eating a favourite meal, or visiting a friend or taking a walk somewhere special.

### **Your exercise programme:**

An exercise programme should include the three different types of exercise; remember they were endurance, flexibility and strength exercise. Following the steps in the box “Steps to success with exercise”, you need to decide on what you want to be able to do and what exercise you would like to do. Now that you know what exercise you are going to do, you need to decide how much to do. The amount of exercise you are going to begin with will depend on a lot of different things. If you have not done any exercise for a long time or have been feeling unwell, have had difficulty breathing or been short of breath, if you have had stiffness or pain or weakness that interferes with your daily activities then you need to start your exercise slowly. You can begin slowly by starting with some flexibility and strengthening exercises. Do these exercises every other day for 5 minutes. Once you can do that comfortably and without feeling stiff or sore the next day, increase it to 10 minutes. Once you can do 10 minutes comfortably, you can start doing the exercises every day (when we say exercise every day, we usually mean exercise for 5 days of the week; it can be very hard to keep a routine to exercise on weekends when activities are different). Once you can do at least 10 minutes every day then you are ready to begin endurance exercises. Choose your exercises from the ones set out in the sections below. Follow the instructions in the box to make sure you get the most out of the exercises and do them safely.

### Getting the most out of your flexibility and strength exercises:

- Move slowly and gently. *Do not* use jerking or bouncing movements as these will make your muscles shorter and tighter.
- Stretch to the point of *tension* in a muscle and hold for 20 seconds before you relax
- Don't push until it hurts, *stretch to tension not pain*
- Start off with 5 repetitions of each exercise. After 1 week increase it to 7, after another week increase to 10.
- Always do the *same number* of exercises on the left side and the right side of your body
- *Keep breathing*; do not hold your breath when you exercise. Think about breathing out as you move to make sure you do not hold your breath.
- Use the *two hour rule*. If you have increased symptoms for more than two hours after you exercise you have probably done too much. Don't stop doing the exercises but decrease how much you do next time.
- If you find an exercise difficult this does not mean you should not do it at all. You should adapt it, do it as completely as you can.

#### Flexibility Exercises:

Remember, these exercises are aimed at improving your ability to move. There is a long list of exercises that could be included here and you might not be able to do them all every time you exercise. Try to ensure that you do flexibility exercises at least once a week.



#### Strengthening Exercises:



You do not need to go to a gym to do strength exercises, the exercises described here can be done at home. To make muscles stronger you must make them work against a resistance or a force – they have to push or pull. You should not do strength exercises every day, rather they should be done every second day. Your muscles need a day of rest to adapt and get stronger. To make a muscle stronger you need to repeat each exercise 5 times to start with.

Once you can do an exercise 10 times you will not get stronger by doing more exercises. Now you will need to add more resistance to the exercise to get stronger.

### Endurance Exercises:

The most difficult thing for most people is deciding how much exercise to start with. The easiest starting point is to ask yourself the question: “how much do I think I can do without suffering for it tomorrow?” If you feel you can do 5 minutes, then do 5 minutes. Remember that any exercise is better than none. You don’t have to do 30 minutes from the first day. It is important to start slowly and increase very gradually. It is better to start off by doing less than you think you can and increase it from there.

There are three things you need to think about when you do endurance exercise. These three things are *frequency* (how often am I going to do this exercise); *duration* (how long am I going to exercise for when I do exercise) and *intensity* (how hard am I going to work when I exercise).



### **Frequency:**

Try to do endurance exercise 3 or 4 times a week. By doing this you can rest every second day and allow your body to recover. All athletes have at least one day a week when they rest. Rest does not mean that they lie in bed all day though, it means that they do not do their exercises.

### **Duration:**

How much can I do without suffering for it tomorrow? That is your starting point. If you are starting with just a few minutes you can gradually increase it over time until you can do 30 minutes at a time. The easiest way to increase the time is to use intervals of exercise. For example to walk hard for 3 minutes, then walk slowly for 2 minutes, then walk hard again for another 3 minutes. Slowly over time cut down the slow walking and increase the hard walking. You could also break your exercise into separate sessions. You could walk for 10 or 15 minutes in the morning and do it again in the evening. This would still count as 30 minutes of exercise.

### **Intensity:**

How will you know that you are exercising hard enough to be doing some good? How will you know if you are exercising too hard? When doing endurance exercise the easiest way to check the intensity is to use the “Talk Test”. When you are doing moderate intensity exercise you should be able to talk comfortably but if you tried to sing it would be a little difficult and you would have to stop singing to take bigger breaths. Moderate intensity means you should feel that you are breathing a little faster and a little harder but you can still talk. It may take you a while to find the right intensity for you for the whole of your exercise session. This is normal; take your time to get to know how your body will respond.

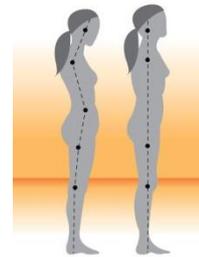
How will you know you are improving in your exercises? For the flexibility and strength exercises it is easy to feel the improvements as you will feel that moving is easier and you are stronger and can lift heavier items. For some people it is harder to know if you are improving with the endurance exercises. One way to see if you are improving is to do a test. One of the easiest tests to do is a timed test. Decide on a route that you can walk near your home. Walk this route at a moderate intensity and time how long it takes. After several weeks of exercise walk the route again and time it again. You may see that you can walk the same route faster within 4 weeks, but it may take 8 to 12 weeks before you see that you can do the route in a faster time. The goal is to complete the same route faster or in the same time but at a lower intensity (breathing much easier).

Use the exercise diary at the end of each section to record your goals and your progress in achieving them.

### Exercise Routine

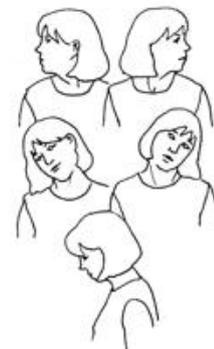
This is a 20 minute exercise routine which is safe for people living with HIV. This routine includes exercises which make you stronger (strength exercises), more flexible (stretching exercises) and fitter (endurance exercises).

1. Start by standing up straight and tall, feel your weight across your feet, relax your shoulders and open your chest, hold your head straight. Take a deep breath in and breathe out.



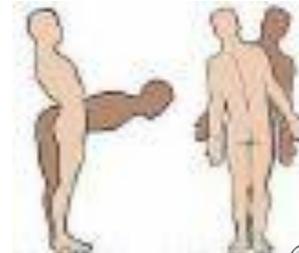
2. March on the spot for 2 minutes. March at a steady pace – that is a pace which you can maintain for 2 minutes. Do not start fast and get slower or start slowly and get faster. Pace yourself, start and finish at the same speed. You should be marching so that you can feel you are breathing a little bit harder than normal, you should be able to talk but not be able to sing.

3. Now stretch your neck – keep your shoulders relaxed and turn to look over your right shoulder – hold it for 20 seconds. Bring your head back to the middle, then turn to look over your left shoulder – hold it for 20 seconds and then bring your head back to the middle. Now put your left ear on your left shoulder - hold it for 20 seconds and then bring your head back to the middle. Repeat to the right. Now put your chin on your chest - hold it for 20 seconds and then bring your head back to the middle. Roll shoulders forwards 5 times, then roll your shoulders backwards 5 times.

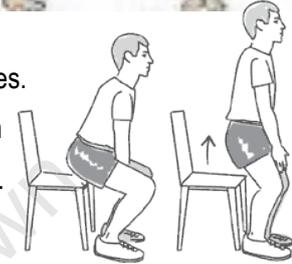


4. March on the spot for 2 minutes – 30 steps normal, 30 steps lift your knees up as high as you can. Keep changing every 30 steps.

5. Stretch your body – with your feet shoulder width apart, slide your right hand down your right leg so that you bend sideways. Bend as far as you can - hold it for 20 seconds and then stand up straight again. Repeat this to the left. Put your hands on your bottom; bend your body backwards as far as you can. Now bend forward and try to touch your toes.



6. Sit on a chair – now stand up, keep sitting down and standing up for 2 minutes. Stand up and sit down at a steady pace – that is a pace which you can maintain for 2 minutes. Do not start fast and get slower or start slowly and get faster. Pace yourself, start and finish at the same speed.

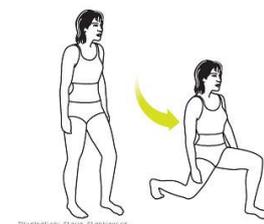


7. Lie down on the floor with your knees bent and your arms crossed on your chest. Lift your head to put your chin on your chest, now lift your shoulders off the ground. Slowly lower down. Keep going for 2 minutes.



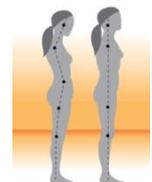
8. March on the spot for 2 minutes – 30 steps normal, 30 steps lift your feet up as high as you can (try to kick your buttocks). Keep changing every 30 steps.

9. Stand up straight. Take one big step forward with your right foot and bend your knees so that your left knee almost touches the ground (lunge). Push back with your right leg to bring your feet back together again. Repeat on the left. Do 10 lunges on each leg.



10. March on the spot for 2 minutes – 30 steps normal, 30 steps lift your knees up as high as you can. Keep changing every 30 steps.

Finish by standing up straight and tall, feel your weight across your feet, relax your shoulders and open your chest, hold your head straight. Take a deep breath in and breathe out.



# Action Plan Form - Exercise

Use this form to develop an action plan on exercise. What exercise would you like to do?

Be sure your action plan includes:

*What* you want to do

*How much* you are going to do

*When* you are going to do it

*How many* days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

\_\_\_\_\_ (*what*)

\_\_\_\_\_ (*how much*)

\_\_\_\_\_ (*when*)

\_\_\_\_\_ (*how many?*)

How confident are you that you can complete this action plan?

\_\_\_\_\_

Not at all										Totally	
confident	1	2	3	4	5	6	7	8	9	10	confident

Keep a record of how you did:

	I Plan to.....	I did.....
<b>Monday</b>		
<b>Tuesday</b>		
<b>Wednesday</b>		
<b>Thursday</b>		
<b>Friday</b>		
<b>Saturday</b>		
<b>Sunday</b>		

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## *Week 2: Managing Common Symptoms of HIV*

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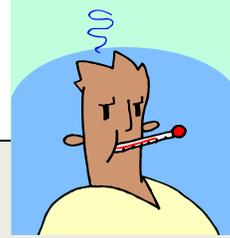
When something that is happening to our bodies that is unusual or not right, we develop symptoms. Symptoms include things like having a fever or temperature, feeling nauseous, vomiting, feeling tired, having pain, having a skin rash, coughing or struggling to breathe, feeling depressed and many, many more. People living with HIV/AIDS are likely to have many different symptoms which need to be managed. In this section, you will learn about *some* of the more common symptoms which people living with HIV/AIDS experience. You will also learn how to manage these symptoms. If you start feeling a symptom which is not described in this section then it is best for you to go to your clinic to get your symptom checked by a doctor or nurse.

The symptoms that people living with HIV/AIDS get can be put into one of three groups. The symptoms may be a side-effect of the medicines that you are using. Information on the side-effects of medicines can be obtained from your clinic and from other support and treatment literacy groups such as the Treatment Action Campaign (TAC). The second possible cause of symptoms is HIV-related infections. You might have a cough because you have developed pneumonia or TB. The third possible cause of symptoms may be the HIV itself. People with chronic illnesses like diabetes, high blood pressure, arthritis and HIV will all get symptoms related to the illness. These symptoms tend to increase and decrease over time. Research tells us that all symptoms can be managed better by following a good programme for living well as using the steps described in this workbook.

### **Symptom Management**

All of the different activities described in this workbook will help you to live well and manage different symptoms. Exercise, eating well, using relaxation techniques and managing stress are all important to help prevent new symptoms from developing. Before we go through the most common symptoms which people with HIV/AIDS experience, there are a few principles to keep in mind when you experience a new symptom. If it is a new symptom, it could be a sign that you are developing an infection or it might be a side effect of a drug. Use the information in this section to help you decide on what action you need to take for the new symptom. It might be something that is safe for you to manage to home, or it might be something that you need to go to the clinic for, or you might manage at home for a while but if it doesn't get better then go to the clinic. Use the charts in this section to help you decide on how to deal with some of your symptoms

If you start experiencing a symptom you need to take time to think about it. Is this a new symptom, one you have experienced before or a symptom you have had for a while which is getting worse? You can do a FAST check (as described in the box below) on any new or worsening symptoms.



**FAST check for new or worsening symptoms:**

<b>Fever</b>	Do you also have a fever which started with the new symptom?  (temperature of more than 38°C)	Having a temperature or fever can be a chronic symptom of HIV/AIDS. But if a fever starts with another symptom it can be an important clue that you have developed an infection.
<b>Altered mental status</b>	Have you also noticed a change in your mental state with the new symptom?	The brain is a very sensitive part of the body. Altered mental status is the term used to describe feeling confused, dizzy, and very sleepy. It can also mean more severe problems like coma or experiencing seizures or fits. You may need your friends or family to help you assess this.
<b>Severe</b>	Is this symptom much more severe (worse) than anything you have had before?	Symptoms come and go but if it is much worse than ever before you need to have it checked.
<b>Typical</b>	Is this symptom not typical for you?	Anything that is totally new and you have never had before, it is best to discuss it with a health care practitioner. You can use the charts in this workbook to decide whether you need to go to the clinic immediately or if you can wait until your next planned visit.

Once you have done your FAST check you can then use the action charts in this section to help you decide what to do next. When you read the action charts, you need to start at the top and follow the arrows depending on your answers to the questions. Do not jump around the chart as this will lead to mistakes. You will see on the chart that some symptoms mean that you need to go to your clinic straight away (now), some symptoms you need to go to the clinic today, and some symptoms you can manage yourself at home until your next routine clinic appointment. If you have more than one symptom, check the charts for all the symptoms and follow the most conservative (safest) advice. If your symptom is not described in this workbook then go to the clinic today to get it properly assessed. We will now discuss some of the symptoms in alphabetical order.

## Breathing problems and coughing



Your body uses coughing to protect your lungs and to remove abnormal things from your lungs. Anything that irritates your lungs can cause you to cough. Coughing might bring up infected pus or mucous from the lungs which is useful. Coughing can be a side effect of medication used for high blood pressure too.

Smoking is one of the most common causes of coughing as the smoke kills cells in the breathing tubes to the lungs. This can happen even in people who are not smoking themselves but are breathing in other people's smoke. Other common causes of coughing are "colds" and "flu" which often cause yellow or white mucous. Infections of the sinuses



(the passages of the nose), can cause coughing because the mucous drips down from the back of the nose into the throat and lungs which irritates them and makes you cough. This is usually worse at night. Another common cause of coughing is hay fever. Hay fever is more common in spring and when it is windy. Dust from tree flowers

(pollen) and plant seeds in the air make it worse. If you are coughing because of hay fever, you will also have either itchy, red eyes and / or a bit of a sore throat with sneezing. The clinic can provide you with anti-histamine medicine to help with this.

### **Cough Action Chart:**

Are you also short of breath at rest or short of breath with walking around?	Yes →	Go to the clinic now
No ↓		
Is your cough dry and do you also have a fever?	Yes →	Go to the clinic today
No ↓		
Do you also have a fever and pain in your chest with your cough?	Yes →	Go to the clinic today
No ↓		
When you cough do you cough up thick, bad-smelling brown or green mucous?	Yes →	Go to the clinic today
No ↓		
Have you had a fever for more than 4 days or has your cough lasted for more than 10 days?	Yes →	Go to the clinic
No ↓		
Treat your cough at home		

People living with HIV/AIDS are also vulnerable to developing lung diseases which cause coughing. The first serious cause of coughing in people living with HIV/AIDS is TB. Tuberculosis of the lungs (TB) causes a cough which lasts a long time with a fever. If you have a cough which lasts for **more than 10 days** then TB should be suspected and you should go to the clinic. The second serious cause is *Pneumocystis pneumonia* (PCP). PCP causes a dry cough (there is no mucous) with a fever and shortness of breath. Take a look at the “cough action chart” and you will see that any cough that also has a fever means you need to go to the clinic straight away.

**Home treatment for a cough:** You can treat your cough at home by making sure you are not dehydrated. If you do not have enough fluid in your body it will make the mucous in your lungs dry and sticky and more difficult to cough out. Drinking a lot of water will help with this. If you have a shower then having a hot steamy shower may also help, or steaming with hot water or rooibos tea will help. If you have a dry cough with tickling in your throat, it may help to suck on cough lozenges or on a hard sweet.

### Depression:

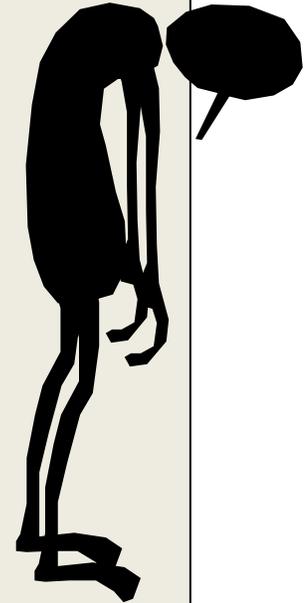
It is common for people living with HIV/AIDS to become depressed but this is often not picked up by the nurses and doctors at the clinic. It is important for you to tell your nurse or doctor if you think you have depression. Depression is an illness, it is not simply the shock, scared, lonely and stressed feelings you probably experienced when you first heard your HIV status. Those feelings are a normal reaction to learning about your status. Depression develops over a few weeks and is a general feeling of depressed mood which happens with physical symptoms. This is caused by an imbalance of chemicals in the brain. See the depression checklist below – if you think you have depression and you have many of these symptoms then you probably have some degree of depression. This can be treated with medicine and psychological support. It is not something to be ashamed of. Go to the clinic and tell the nurse or doctor how you are feeling so that they can start you on treatment.



Dementia is very different from depression. With dementia your thinking is affected so that you struggle to communicate, you may struggle to pay attention and forget things a lot. You may also find it hard to move, be clumsy, lose your balance or even find that you can't move at all (paralysed). Your personality might also change. People who develop dementia generally do not feel depressed as they are usually not aware that they are unwell. Dementia is treated with ARV's.

### Depression Check List:

- Do you feel down most of the time?
- Do you lack enjoyment with fun things like music, soccer or chocolate?
- Do you try to find peace by overeating?
- Or do you lack appetite and lose weight?
- Do you sleep badly at night?
- Do you struggle to get up in the mornings?
- Do you feel angry and agitated very quickly?
- Do you feel very passive?
- Do you lack energy every day?
- Do you struggle to concentrate?
- Is it difficult to make decisions about simple matters?
- Do you feel guilty?
- Do you feel worthless sometimes?
- Do you think of death a lot?
- Do you think of killing yourself?



*If you answer yes to many of these questions, then you may have some degree of depression.*

*Speak to the doctor or nurse at the clinic about how you are feeling.*

*If you answer yes to one or two of these questions then you may have depressed mood which you can manage with some of the techniques described in the section on stress management.*

**Home treatment for Depression:** There are many things you can do to help manage depression. Make sure that you get help straight away if you *feel like hurting yourself or someone else*. Often talking to a person who understand or to a health professional will help you through this mood. *Cut back on alcohol*, although it might make you feel better in the short term. In the long term it affects the way your brain works and you will not be able to escape the depression. *Keep active*, make you sure you get up every day, get dressed and get out of the house. Even if you don't feel like doing things, it's important to keep active, visit friends, and join a group. If you start to lose contact with people and withdraw your mood will only get worse. Make *plans for the future*, for tomorrow, for next week, for next month. Make sure you do *20 to 30 minutes of exercise every day*. As we said in Week 1, exercise is very important to keep us healthy and help our moods. Depression feeds on depression, when you believe that things will get better, they will start to change. Use the suggestions in the section on Week 3: Stress Management to help you manage your symptoms.

### Diarrhoea (Running tummy)

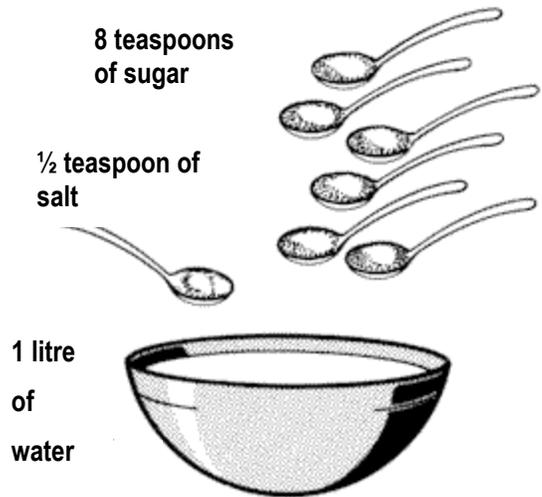
Diarrhoea can affect anyone. Diarrhoea means you have to go to the toilet often and / or your stool is watery or slimy. Sometimes diarrhoea comes with stomach pains or with vomiting or both. When you have diarrhoea your body is losing water all the time. Losing water is called dehydration and can be dangerous, especially for children.

Diarrhoea can be because of infections, as a side effect of medicines or caused by poor absorption of food. Diarrhoea can be prevented by making sure that you are using clean drinking water, that you prepare food carefully (see the section for Week 5) and make sure that you wash your hands every time after going to the toilet.

**Diarrhoea Action Chart:**

Do you have?		
• <i>Black or bloody stools</i>	Yes	Go to the clinic now
• <i>Severe, steady stomach pain</i>	→	
	No ↓	
Do you have any signs of dehydration?		
• <i>Extreme thirst</i>	Yes	Go to the clinic today
• <i>Very dry mouth</i>	→	
• <i>Dark urine</i>		
• <i>Lightheadedness</i>		
	No ↓	
Are you taking antibiotics?	Yes	Go to the clinic
	→	
	No ↓	
Has the diarrhoea lasted for more than 5 days without improving?	Yes	Go to the clinic
	→	
	No ↓	
Treat your diarrhoea at home		

**Home treatment for diarrhoea:** The most important thing with diarrhoea is to make sure that you are getting enough fluids so that you do not become dehydrated. Try to avoid drinks with caffeine in them as they can cause more dehydration (coca-cola, coffee and tea all have caffeine). Drink your fluids at room temperature, hot drinks or cold drinks can make your diarrhoea worse. Making a **glucose drink** is the most effective treatment for diarrhoea. Make this by filling a clean one-litre bottle with clean water from a tap or boiled water if you are not sure that the water is clean. Add 8 teaspoons of sugar and half a teaspoon of salt to the water and mix it well. You can add half a cup of orange juice if you find you don't like the taste. Try to drink one to two cups (200ml) after each loose stool (bout of diarrhoea). Take small sips and drink it slowly.



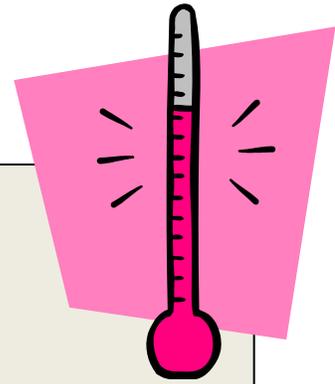
If you have diarrhoea you might not feel like eating but skipping food is not a good idea. Try plain foods like dry toast white rice noodles, mashed potatoes or white bread. Eat any food that doesn't make you feel sick. Make sure you wash your hands before and after handling food. Usually diarrhoea will go away on its own within a week.



### Fever

Fevers or having a high temperature are most commonly caused by infection. In people living with HIV/AIDS the fever can be caused by the HIV itself but it can also be caused by other infections or even by medications. If you have a fever you need to check that you do not have any other symptoms of serious illness warning you to take action straight away. Use the fever action chart to check for these.





## Fever Action Chart:

Do you have a fever and?

- Neck stiffness (you can't bend your neck to put your chin on your chest)
- Extreme tiredness or feel confused
- Fitting or seizures
- Severe irritability

Yes

→ Go to the clinic now

No ↓

Do you have a fever with a dry cough and severe shortness of breath?

Yes

→ Go to the clinic now

No ↓

Do you have a new skin rash or skin sores with this fever?

Yes

→ Go to the clinic

No ↓

Do you have any of the following with your fever?

- Headache
- Sore throat
- Cough
- Diarrhoea
- Urinary problems

Yes

→ See the action plan for that problem

No ↓

Treat your fever at home

**Home treatment for fever:** A high fever can be treated by sponging the body down to cool it down, or by using medicine. Sponging the body down with luke-warm water (not cold water) helps to bring the temperature down. Paracetamol (Panado) can also be used to lower a temperature.

## Headaches:



Headaches are one of the most common symptoms experienced by people both with and without HIV/AIDS. Headaches can be caused by muscles becoming tense, they can also be caused by medication. Headaches with fevers can be more serious. If you have a headache with a fever and stiff neck – *a neck so stiff that when you bend it forward you can't put your chin on your chest*, you may have meningitis. This is a serious infection of the lining of the brain which needs to be treated immediately. Use the headache action plan to decide how to manage your headaches.

### Headache Action Chart:

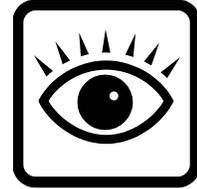
Do you have a <i>fever and neck stiffness</i> with your headache?	Yes →	Go to the clinic now
No ↓		
Do you have any of these with your headache?		
• <i>Difficulty moving your arms or legs</i>	Yes	Go to the clinic now
• <i>Difficulty with seeing</i>	→	
• <i>Difficulty speaking (slurring)</i>		
No ↓		
Has your headache lasted more than 3 days?	Yes →	Go to the clinic
No ↓		
Treat your headache at home and discuss it at the clinic at your next routine appointment		

**Home treatment for Headaches:** Paracetamol is very effective to treat a simple headache. This medicine works better if you take it as soon as you feel the headache rather than waiting until the pain is so bad you can't take it anymore. If the headache is due to muscle tension and stress then rubbing the neck muscles and putting something warm on the neck (a hot water bottle wrapped in a towel) can help. Relaxation techniques and resting is also very effective to manage headaches.



### Eye problems:

People living with HIV/AIDS can get many eye problems. All eye problems should be checked at the clinic. Eye problems can be caused by infection (CMV), but, eye problems can also be caused by medicines, high blood sugar (diabetes), headaches, eye strain and normal changes with ageing. If you develop eye problems *suddenly* then it is likely that this is caused by an infection and you need to go the clinic straight away. If your eye problems have come on slowly then you need to get your eyes checked the next time you go to the clinic.



#### **Eye Problem Action Chart:**

Did <i>blindness</i> (part or total) come on <i>suddenly</i> in one or both eyes or is <i>the loss of vision severe</i> ?	Yes →	Go to the clinic now
No ↓		
Is your CD4+ count more than 200	Yes →	Go to the clinic
No ↓		
Have you had <i>gradual loss of vision equally in BOTH</i> eyes	Yes →	Go to the clinic
No ↓		
Go to the clinic NOW		

### Nausea and Vomiting:

Many of the worries about nausea and vomiting are the same as for diarrhoea. Medicines are most common cause of nausea in people with HIV/AIDS but this can also be caused by viral infections. Dehydration is the biggest risk. Signs of dehydration may be dizziness, severe thirst, dry mouth and tongue, decreased and very dark urine, wrinkled and dry skin. Black or bloody vomit can be a sign that there is bleeding in the stomach.



the



## Nausea and Vomiting Action Chart:

Do you have any of these?

- *Black or bloody vomit*
- *Severe steady stomach pain*
- *Headache with a stiff neck (you can't put your chin on your chest)*

Yes



Go to the clinic now

No ↓

Do you have any signs of dehydration?

- *Extreme thirst*
- *Very dry mouth*
- *Dark urine*
- *Lightheadedness or dizziness*

Yes



Go to the clinic now

No ↓

Has this started after starting *new medicines*?

Yes



Go to the clinic

No ↓

Are you pregnant or do you think you might be pregnant?

Yes



Go to the clinic

No ↓

Have you been vomiting for *more than 3 days without improvement*?

Yes



Go to the clinic

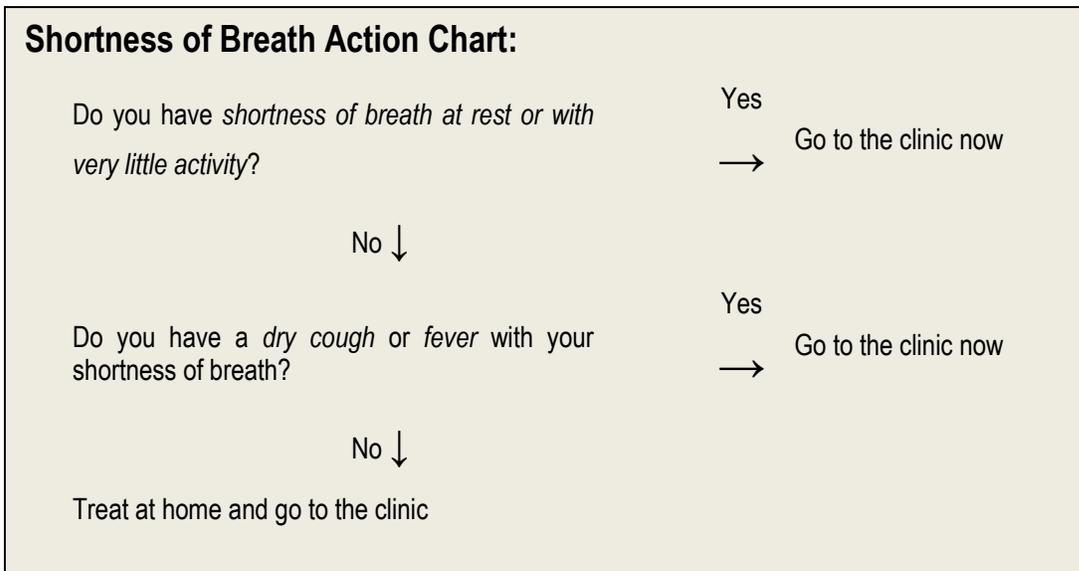
No ↓

Treat vomiting at home

**Home treatment of Nausea and Vomiting:** It is important to get as much fluid into your body as possible without vomiting again. Sipping the glucose drink described for diarrhoea is important. Don't try to drink a whole glass all at once, sip it slowly so that you do not vomit again.

### Shortness of Breath:

It is normal to feel short of breath when you do strenuous activity or exercise. If you get short of breath when you are resting or when you do very little activity or if you wake up at night feeling short of breath then you need to go to the clinic urgently. The main cause for this kind of problem in people with HIV/AIDS is PCP. Shortness of breath can also be caused by lung infections you have had in the past and smoking.



**Home treatment for Shortness of Breath:** If you are busy with something when you become short of breath you should not stop straight away or try to hurry up to finish. It is best to slow down what you are doing and see if your breathing settles down. Sometimes when we feel short of breath we worry about it which makes us afraid and can make our breathing even worse. If you have not been very active for a while, your shortness of breath might be a sign that you need to get fitter. You need to slowly increase your activity over time as discussed in the section on exercise. If you smoke and you are getting short of breath you need to try to stop smoking. If you are struggling with stopping smoking then speak to the nurse on your next visit to the clinic. If people smoke near you, try to avoid their smoke or ask them to smoke away from you. If you are short of breath it is helpful to practice the deep breathing exercises described in the section on relaxation. This kind of deep breathing helps to train the muscles for breathing and also helps your mind to manage your symptoms.

### Sore Throat and mouth:

Sore throats are common in people with and without HIV. The most common causes of a sore throat are the cold viruses but a sore throat can also be caused by other infections. Most sore throats can be treated safely at home. A sore mouth and sore ears are also common. Patches in the mouth, white patches on the tongue or mouth or red burning patches which are itchy and sores in the mouth or down your throat can all be caused by thrush. Pain in the mouth can be caused by teeth with holes. Teeth can get holes because of bacteria in the mouth. You can prevent these by brushing your teeth twice a day and after every meal. It does not take much toothpaste (a drop the size of a pea is enough) to keep your teeth clean. It is also important to cut down on sweets and fizzy drinks which cause teeth to rot. Use the sore throat and mouth action chart to decide on what you need to do.



#### **Sore Throat and Mouth Action Chart:**

Do you have severe difficulty breathing or swallowing?	Yes →	Go to the clinic now
No ↓		
Do you have a fever or pus in the back of your throat?	Yes →	Go to the clinic
No ↓		
Do you have pain in your teeth or swelling in your cheek?	Yes →	Go to the dental clinic
No ↓		
Do you have sores or white patches in your mouth, on your tongue or on your lips?	Yes →	Go to the clinic
No ↓		
Has your sore throat <i>lasted more than 10 days</i> ?	Yes →	Go to the clinic
No ↓		
Treat at home		

**Home treatment for a sore throat and mouth:** Drinking cool liquids and taking painkillers like paracetamol can help. You can also treat a sore throat by gargling with salt water. It may also help to suck on ice cubes if you have access to ice.

## Skin Problems:

There are many skin problems which can affect people living with HIV/AIDS. Very few of these problems are dangerous but because they can be seen they can be very upsetting. Being able to see these might make you feel unattractive or have low self-confidence, they often last a long time and can constantly remind you of your HIV status. The most common skin problems people with HIV/AIDS have are shingles, chicken pox, bacterial infections, warts, fungal infections and rashes.



<b>Skin Problems Action Chart:</b>		
Do you have a rash which is <i>painful</i> on one side of your body or on your face?	Yes →	Go to the clinic today
No ↓		
Has the rash started after starting new medicines?	Yes →	Go to the clinic today
No ↓		
Do you have a rash or blisters on your body and a <i>fever</i> ?	Yes →	Go to the clinic today
No ↓		
Do you have warts on your skin which are a different colour to your skin?	Yes →	Go to the clinic
No ↓		
Do you have a rash in a <i>circle</i> on your skin or <i>white dying skin</i> between your toes, in your groin, around your private parts or under your arms or is there <i>pus in the rash</i> ?	Yes →	Go to the clinic
No ↓		
Treat at home		

**Home treatment for skin problems:** It is important to keep the skin clean to prevent any infections developing. Wash your whole body with soap and water every day. Keep your fingernails short and clean. If you are scratching in your sleep, you can sleep with socks over your hands so that you do not damage your skin. If your skin is dry and itchy, it helps to wash with aqueous cream instead of soap.

## Urination problems:

Urinary infections happen more often in women than in men, but men with HIV/AIDS are more likely to get these infections too. The most common symptom of a urinary infection is pain or burning when you pass water, frequent need to pass water and blood in the urine. These symptoms are not always caused by an infection; they can also be caused by too much caffeine (tea, coffee, cola); bladder spasms (when the bladder becomes overactive) and even anxiety. Bladder infection in women can also be caused by sexual activity. If you also have a fever, vomiting, back pain or teeth-chattering or body-shaking chills it is likely that the infection has spread from the bladder to the kidneys. Use the Urination Problems Action Chart to help you decide how to manage your symptoms.



### **Urination Problems Action Chart:**

Do you have a <i>fever, vomiting, back pain, shaking chills</i> as well as <i>painful or frequent or bloody urination</i> ?	Yes →	Go to the clinic today
No ↓		
Could you be pregnant?	Yes →	Go to the clinic today
No ↓		
Do you also have a <i>new irritating vaginal discharge</i> ?	Yes →	Go to the clinic today
No ↓		
Do you have pain in your stomach (abdomen) as well as a vaginal discharge?	Yes →	Go to the clinic today
No ↓		
Treat at home and go to the clinic if it does not clear up in 2 days.		

**Home treatment of urination problems:** The first step in managing these problems is to drink a lot of water. Drink several litres (4 to 5 litres) of water in the first 24 hours after these symptoms start. This helps to wash out anything which might be causing the problem. Drinking fruit juices can also help as these change the chemical content of the urine. If you have a new vaginal discharge or pain in the abdomen it is important to go to the clinic as this means that the symptoms may not be coming from the bladder but from the vagina which needs medical treatment.

### A final word on symptoms:

Remember the steps described in this section and the action charts do not replace nurses and doctors. The information in this section is to help you work **with** your health team. Use the action charts to help with thinking about any symptoms you experience and to help you decide what you need to do about them. As you have read, some symptoms it is perfectly safe for you to manage at home. Some symptoms you need to go to the clinic straight away for. If you have any doubt or any worries about any of the symptoms you experience then it is best to go to the clinic to get them fully assessed. Remember what you learnt in the first section on how to be a good self-manager. Use the information in that section to help you get the most out of any visit to the clinic about any symptoms you experience.



When you do visit the clinic for a symptom you may be treated by the nurse or doctor. Or may be referred to someone who specialises in the problem you are experiencing. In the next section, we will discuss how to communicate well with your health carer. No matter who you are seeing at the clinic, it is useful to use the steps on communication to get the most out of your clinic visit.

Use the “Action Plan Form” at the end of this section to plan how you will manage a symptom which you experience. Use the “Exercise Diary” to keep track of the exercise plan you started last week. Remember these charts are designed to help you become a successful self-manager!

## Action Plan Form – Managing Symptoms

Think about a common symptom which you experience. Use this form to draw up an action plan of how you plan to manage this symptom the next time it occurs.

Be sure your action plan includes:

*What* you want to do

*How much* you are going to do

*When* you are going to do it

*How many* days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

\_\_\_\_\_ (*what*)

\_\_\_\_\_ (*how much*)

\_\_\_\_\_ (*when*)

\_\_\_\_\_ (*how many?*)

How confident are you that you can complete this action plan?

\_\_\_\_\_

Not at all											Totally
confident	1	2	3	4	5	6	7	8	9	10	confident

Keep a record of how you did, when I feel sick:

	I Plan to.....	I did.....
<b>Monday</b>		
<b>Tuesday</b>		
<b>Wednesday</b>		
<b>Thursday</b>		
<b>Friday</b>		
<b>Saturday</b>		
<b>Sunday</b>		

# Exercise Diary

Use this exercise diary to keep track of the exercise goals and plan you drew up in week one.

Start off by writing down your goal.

Write down here what you want to be able to do: \_\_\_\_\_

Now, what do you want to be able to do this week which will help you to reach your goal?

Remember from your action plan to include:

*What* you want to do

*How much* you are going to do

*When* you are going to do it

*How many* days a week you are going to do it



For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

\_\_\_\_\_ (*what*)

\_\_\_\_\_ (*how much*)

\_\_\_\_\_ (*when*)

\_\_\_\_\_ (*how many?*)

	<b>Exercise Planned</b>	<b>Exercise I did...</b>	<b>How did I feel? Do you need to change anything?</b>
<b>e.g.</b>	<i>20 mins in a.m. after breakfast and in p.m. after supper</i>		<i>Very tired by the second session, I'm going to cut it down to morning only for this week.</i>
<b>Monday</b>			
<b>Tuesday</b>			
<b>Wednesday</b>			
<b>Thursday</b>			
<b>Friday</b>			

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## Week 3: Stress Management

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In our society, we talk about stress a lot. We might say that it is stressful to live in South Africa. That it is stressful to worry about our children or our families, it is stressful to worry about money or it is stressful worrying about getting a job or coping with my job. We use the word stress a lot, but what does it mean? Stress is a feeling; it is a combination of feeling tense and worried. When we feel stressed we may be irritable, and find it difficult to concentrate or remember things, stress can affect our sleep, our appetite and our relationships.



The most common reason why we feel stressed is a lack of control. We tend to feel that things are stressful if we don't have any control over them. We feel stressed if we are going to be late for work because the trains are late – this is out of our control. We feel stressed about where we live if we don't feel safe there – those who commit crimes against us are also out of our control. In the same way, we may feel stressed when we have a chronic illness like HIV/AIDS or diabetes or high blood pressure. If you feel that your illness is out of your control and there is nothing you can do to affect it, this makes you feel stressed.



Stress is not always bad. We know that stress can be useful too. For many people if we feel some stress, we might feel under pressure to perform better. You might feel stressed because your family is coming to visit, but this stress makes you tidy up your home – a good effect of the stress. Students who are studying will only complete their studies if there are exams and deadlines for assignments, without the stress of the deadline, the students would not complete the work.

Sometimes we wish for a “stress-free” life. But, we know that if there was no stress in our lives, if we did not have to do anything all day long, this would not be good for us either. If I lay in bed all day and did not do anything, my muscles would get weak, my joints would get stiff and I would become ill. We need some stress in our lives to keep us healthy. The important thing is to keep the amount of stress at a level that we feel we can manage. This is why we talk about stress management, *not* stress elimination!

There are many different things we can do in our lives to manage stress. The first step is to understand why we are feeling stressed. There are usually three things which affect how we stressed feel.

### **1. The stressful situation:**

Usually the less you expect the situation and the less familiar you are with a situation, the more stressful it will be. If you needed to take the train to work but you knew the day before that the trains would be late, this would be less stressful than finding out after you have got onto the train that it is going to be late. If you think about having pain, if you know the cause of the pain is it more or less stressful? If you don't know what is causing your pain and you are worrying that there is something seriously wrong, is this more or less stressful?

### **2. How you see the situation and how you cope with it:**

If the situation you are in is not important, you are likely to feel less stressed about it. If you are on a train which is going to be late, but you are going shopping on your own, then you are likely not to get so stressed about it. If you are on a train which is going to be late and you are going to work this might be more stressful, but if you have a cell phone with you and you have airtime on the cell phone and you telephone your boss to explain why you will be late, then this might be less stressful. Your ability to cope with the situation, affects the amount of stress you feel. While it is stressful to live with a chronic disease like HIV/AIDS, diabetes or high blood pressure, if you thought you could cope with it and it would not interfere with your job and your life would it be more or less stressful? Having knowledge about your condition allows you to think about it in a different way and will change the way that you cope.



### **3. Support from family and friends:**



Friends and family who understand and support you will affect your levels of stress. Feeling alone and like you have no support will probably make you feel more stressed. If you think about living with HIV/AIDS, would it be more or less stressful if there were no one to support you? But, we do need to be careful about support from family and friends. If they take over doing everything for us (because they care about us and are trying to help), we might feel useless and like we don't have a purpose. Support does not mean doing everything for me.

Stress is not just the things that happen to us. The amount of stress that we feel depends on a lot of different things which can change every day. There are many different things we can do to manage stress every day.

## Managing Stress:

### 1. Dealing with the cause of the stress



The first step in dealing with stress is to identify *why* you are feeling this way. Use the self-management steps to help you identify the problem. Once you know why you are feeling this way then you need to decide what you can do about it. Sometimes dealing with the things that stress us is easy, if you are friends with your neighbours and the noise from their television is irritating you it might be easy to ask them to turn down the volume. If you are not friends with your neighbours, or you are very shy it might be quite difficult to ask them to turn down the volume. Sometimes we can identify the things that stress us and do something about it. But, often we either cannot deal with it or it is out of our control. If you cannot deal with it or it is out of your control, the next step is to change the way you are looking at the problem.

The second step is to look at the problem in a different way. Think about how you are feeling. Are your thoughts and feelings about the problem inaccurate? Maybe you are very worried about your health, this is stressing you. Are you worried that you will be very ill and unable to work soon? Are these thoughts and feelings accurate? On what information are you basing these thoughts and feelings? Have you spoken to experts about your health or are you basing your thoughts and feelings and stress on poor information?

Step three is - plan your life. Do you get stressed by the same things over and over again? Or do you find yourself getting stressed because there are times when your life is very busy? If you are doing the same things over and over and getting stressed, you might want to look at how you are dealing with it and see if you can try a different plan. What about a busy life? This is also about planning, being very busy and having no time for ourselves, can be very stressful. Plan things over time carefully, make sure you have time to at least do some relaxation or exercise even when you are very busy. Do not leave things for the last minute.



The last step to deal with stress is to get help. Family and friends and support groups are a great way to decrease stress. If we want support from people though, we have to tell them clearly what the problem is and what we would like from them. Often we do not communicate clearly and this might make the stress worse! If you find your family or friends are not very helpful or supportive, it might be worth sitting down with them when you are not feeling stressed to talk about these things. It might be that they see things differently to you, this does not mean they are right and you are wrong, or that you are right and they are wrong. It just means that you see things differently and you can discuss how to handle things better. If having a discussion like this is difficult, it might be useful to ask a counsellor to help with the conversation.

You can ask for assistance at a clinic or you can go to an NGO like FAMSA who specialise in family and relationship counselling.

## 2. Relaxation

When we feel relaxed, we feel calm. Sometimes if we are relaxed and we are tired, we might feel sleepy. At other times we might feel relaxed and alert and be able to concentrate calmly on tasks. Relaxation can help us to concentrate and it can help us to unwind and go to sleep. Relaxation is a very useful way to manage stress and some of the symptoms of chronic diseases such as pain.

If we are stressed, this can make our muscles tense, our hearts beat faster and we breathe faster, if we are also feeling unwell and have pain we will feel worse. Relaxation can decrease the tension in muscles and slow down our hearts and breathing and help to make us feel better. If we are stressed we often become irritable and moody,



relaxation helps to calm you and make you feel more in control of your life. When we are stressed sometimes it is difficult to fall asleep as we are worrying about things out of our control, if you are also unwell, not sleeping will make you feel worse. Relaxation will help you get to sleep, this will help manage your stress and improve your health.

Just like learning to play a new sport or doing exercise, relaxation takes practice. The specific way that you relax doesn't matter; we are all different and might relax in different ways. The important thing is to practice it regularly. There are two different ways of relaxing described at the end of this section. You can do these at home in a quiet and comfortable safe place to begin with. But, once you get good at relaxation, you can relax in a crowded waiting room, on a train or a taxi. You can do relaxation anywhere!

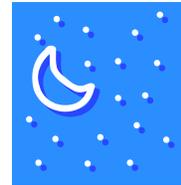
### ***Good times to practice relaxing are when:***

- *You feel you are getting tense or irritable or you are worried*
- *You feel you are in pain*
- *You want to go to sleep*



### 3. Sleep

People with chronic illnesses often struggle to sleep because they are stressed and worried about their condition, they worry about what this means for them, for their family, for their future. People also often struggle to sleep because of the illness itself, perhaps you have pain, you feel sick or you may even be so tired you can't sleep. Some people find it difficult to get to sleep and only fall asleep very late at night, others find that they fall asleep but then wake up during the night and can't get back to sleep. Some people find it difficult to sleep at all at night and sleep during the day.



Sleep is very important to keep healthy. We all need different amounts of sleep. Some people need 8 hours of sleep a night, some may need 10 hours and some people only need 5 hours of sleep. We are all different. We have been learning how to fall asleep and sleep well since we were babies. If you do not sleep well, following these steps will help you to learn how to fall asleep and sleep well. Remember that like learning anything new, this will take time. It might take up to 3 months to learn to sleep well if you have been struggling with sleep for a while.

#### Suggestions for Improving Sleep

1. *Have a bedtime routine:* try to go to bed at around the same time every night and always do the same things before getting into bed. A bedtime routine could be to lock the house, get undressed, wash your face, clean your teeth, get into bed and do a relaxation session.
2. *You can't sleep because of worrying:* write down your problems or the things that are worrying you, then write down the next step that you think could help sort out the problem. If you wake up during the night worrying about the problem, remind yourself that you've gone over it and you have a plan. If you wake up with a new worry, write down that problem to deal with in the morning. Practice your relaxation to take your mind off the worry. If you still can't sleep, it may be better to get up and do something relaxing like reading, watching TV, listening to relaxing music or doing relaxation.
3. *Your bed and bedroom are for sleeping:* try not to use your bedroom during the day. Do not watch TV in bed. If you are not asleep within 30 minutes of going to bed, get up and do something else. Do not lie in bed and worry that you have not fallen asleep. This will only make you feel stressed and lessen the chance of falling asleep.
4. *Have a morning routine:* get up at the same time every day, even if you don't feel like it. Our bodies like to work on regular patterns to fall asleep and get up at the same time every day.
5. *Avoid drinks containing caffeine* for at least 4 hours before going to sleep (drinks like coke, tea or coffee).



6. *Never use alcohol to help you sleep.* It might make you feel relaxed at first, but once this wears off it is likely to make you feel jumpy and you are likely to wake up during the night.

***Good sleep habits:***

- *Go to sleep at the same time every day*
- *Have a bedtime routine*
- *Do relaxation before going to sleep*
- *Use your bed only for sleeping or relaxing*
- *Have a morning routine*

**4. Exercise**



Exercise is a very effective way of managing stress. People who exercise regularly doing at least 20 to 30 minutes of exercise, 3 times a week have less risk of suffering from stress related illnesses. Go back to the section on exercise for more on how to exercise safely and effectively.

***Exercise:***

- *Decreases stress*
- *Helps us sleep better*
- *Decreases pain*
- *Makes us healthy and decreases our chances of developing other illnesses*

## 5. Communicating with your health carer

Anyone living with a long term health problem, whether it is HIV or high blood pressure or diabetes will have to visit their clinic regularly. Visiting the clinic regularly can be stressful because it takes time, you have to plan ahead, you might not be sure how long you are going to have to wait, you might be worrying about what the health carers are going to tell you. One of the most important ways of managing the stress associated with visiting clinics and seeing health carers is to think about and plan how to communicate with them.



When visiting the clinic to see a health care practitioner it is important that you feel comfortable asking questions (any questions, even if you feel they are “silly” or “stupid” questions) and comfortable expressing how you feel. It is also important that you feel you can negotiate your treatment with your health care provider so that both you and the



carer feel that you are receiving the best care for you. It is important that you not feel that your health care provider is ignoring you, “puts you down” or treats you like a child. We know that doctors and nurses have a lot of patients to see and they have little time to spend with each person. One helpful way to make sure that you get the most out of your appointments with the doctor or nurse is for you to take PART – Prepare, Ask, Repeat, Take action.

### Take PART:

#### Prepare:

Before your appointment at a clinic it is important to prepare. Think about the reason for your appointment and whether there are any issues in particular that are worrying you. Write down your questions or the things that are worrying you. You need to be realistic about the list you write down, there will probably only be time to answer one or two of the things on your list. Make sure the most important problems are at the top of the list. Take your list with you to your clinic appointment, then when the doctor or nurse asks if there is anything you want to ask, you can use your list.

If there are particular symptoms or health issues you want to discuss, prepare for your appointment by writing down specific information the doctor or nurse will want to know. Things that are helpful are: when did it start, how long do the symptoms last, where are they in your body, what makes you feel better or worse, have you had a problem like this before and how was it treated; have you changed anything such as your diet, exercise, medicines. If you have already received treatment for a problem, be ready to report back on how well it has worked, or on whether it not worked at all.



has

Be open about how you are feeling and about the things that are worrying you. The more open you are, the more the health care provider can help you. Finally, give feedback. If you don't like the way you have been treated you can tell the doctor or nurse. If you do not want to tell them directly then you can speak to someone else in the clinic or to someone in a support group. Remember too that doctors and nurses and other health care providers also appreciate being complimented. If you feel that you have been treated well and are happy with your treatment, it is acceptable to compliment the health carer.



### **Ask:**

Another important step in having good communication and decreasing stress is to ask questions. Having good information is essential to you being successful in self-managing your health. Ask questions about your diagnosis such as what is wrong, what has caused it, is it contagious and what is going to happen now? Then ask questions if you have had tests, what is the test for; what if I don't have the test and what will the test involve? Remember to ask questions about your treatment options, what are the benefits of treatment and what are the risks and side effects? Finally ask questions about follow-up, when should you return to the clinic, what should you watch out for and what should you do next?

If you find you have difficulty remembering information it is a good idea to write things down during your visit. Or you could ask someone you trust to come to the appointment with you to help with remembering.



### **Repeat:**

One of the important things to do to help with remembering things is to repeat it. So if the nurse or doctor explains something to you, repeat back to them in your own words what you have understood. This is very useful to make sure there are no misunderstandings.

### **Take Action:**

At the end of your appointment, it is important that you know exactly what you will need to do next. It might be that you need to make another appointment, or that you need to go home and change something or get new medicine from the pharmacy. Make sure that you are clear about what you need to do next, and then do it!

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# Relaxation

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## *Long relaxation:*

Find a comfortable position. Lie on your back or sit in a chair with your back supported.

Place your hands at your sides, palms up.

Close your eyes if you wish.

Now begin to become aware of your breathing..... Focus on slowing down the rhythm of your breathing.....

Your chest and tummy will expand outward with each breath, like a balloon gently filling with air....

Imagine your ribcage moving out to the sides when you breathe in.... and gently inward as you breathe out....

Slowly take a deep breath in.... Pause for a moment.... and then slowly breathe out. Let the tension melt away as you relax more deeply with each breath...

Continue breathing slowly and gently....

Now think about the top of your head. Feel the skin on the top of your head beginning to relax, and spreading slowly downwards....

Even your ears are becoming relaxed and heavy.... Feel your eyebrows resting....

Your forehead is becoming relaxed and smooth....all the lines on your face are becoming smooth..

Let your jaw relax by allowing your mouth to be slightly open.... Allow your tongue to relax...

Feel your throat relaxing.... relax your cheeks, nose, and eyes.... Feel your eyelids becoming very heavy.... and very relaxed.... more and more relaxed....

Enjoy the feeling of relaxation you are experiencing.

Now think about your neck.... allow a feeling of relaxation to begin at the top of your neck, and flow downward...

Feel the relaxation as your shoulders become relaxed and loose.... Let your shoulders gently sink downward.... as they become relaxed.... and heavy.... very heavy.... and very relaxed.... deeper and deeper.... relaxed....

Feel your collar bones becoming relaxed as your shoulders move gently back, and your chest widens slightly....

Allow all the muscles in your shoulders to feel smooth... and relaxed.... as the muscles give up their hold completely...

Notice your breathing once again... see how regular it has become... continue to take slow.... smooth.... deep breaths... Breathe in the feeling of relaxation... and breathe out any tension... your breathing allows you to become more and more relaxed.... deeply relaxed..... Now turn your attention to your right arm..... Feel the relaxation flowing down from your right shoulder.... allow your upper arm to relax... your elbow.... lower arm... and wrist become loose and relaxed....

Enjoy the feeling of relaxation as the muscles of your right arm give up their hold.... Feel the relaxation flowing into your hand... Let all the tension drain out of each fingertip and flow away.... the relaxation spreads to your thumb... index finger.... middle finger... ring finger... and little finger....

Feel the relaxation flowing down your left arm... Let the muscles of the left upper arm relax.... Relax your elbow.... lower arm.... and wrist....

Enjoy the feeling of relaxation you are experiencing.

Let the tension melt away.... imagine the tension flowing right out of your fingertips... Allow your left hand to relax completely.... relax your thumb... index finger.... middle finger... ring finger... and little finger....

Both of your arms are now totally relaxed... allow them to be free and limp... pleasantly relaxed...

Enjoy the feeling of relaxation you are experiencing...

Allow the feeling of relaxation to continue to your chest and stomach....feel the relaxation there... becoming deeper with each breath....

Now turn your attention to your upper back... Feel the relaxation flow down your spine... Let all the muscles give up their hold.... relax your upper back... middle and lower back.... allow your back to relax completely..... Feel the relaxation in your whole upper body ....

Relax more deeply with each breath.... more and more relaxed.... deeply relaxed and calm....

Let your hip muscles relax.... Relax all the way from your buttocks (bottom), down the back of your thighs... relax the muscles on the front of your thighs...Feel the relaxation in your upper legs moving down to your knees... your calves and shins.... your ankles.... and your feet.... allow all the muscles to relax and go limp....

Allow any last bits of tension to flow right out of the soles of your feet....Feel the relaxation flowing through your body... From the top of your head... down to the bottoms of your feet.... become more relaxed with each breath.... enjoy the feeling of total relaxation.....

You are now as relaxed as you want to be.... Experience the feeling of deep relaxation... enjoy the feeling.... relaxed.... calm..... at peace

Focus on the feeling of relaxation throughout your body.... Notice your breathing.... Your relaxed muscles.... Your calm thoughts... Memorize this feeling so you can re-create this relaxed state whenever you wish....

Enjoy relaxing for a few moments more....

When you are ready to return to your day, reawaken your body slowly... gently move your muscles... roll your shoulders slowly forward.... then slowly backward.... lean your head gently to the left... return to centre.... lean your head gently to the right... turn your head...

Wriggle your fingers and toes....

Gently open your eyes.... Feeling alert... calm.... and full of energy.

**Short relaxation:**

Deep breathing not only helps to cure anxiety and stress, it also triggers relaxation. Here's how to breathe deeply.

Breathe in slowly to the count of four (count slowly; to the pace of one-one-thousand, two-one-thousand....). Pause to the count of three.

Breathe out slowly to the count of five.

The breathing process goes like this:

Inhale... two, three, four...pause...two, three....exhale...two, three, four five....

Inhale... two, three, four...pause...two, three....exhale...two, three, four five....

Repeat for a minute or two.

University of Cape Town

# Action Plan Form – Stress Management

Think about one thing that is causing you stress. Use this action plan form to come up with a plan of how to manage your stress this week.

Be sure your action plan includes:

*What* you want to do

*How much* you are going to do

*When* you are going to do it

*How many* days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

\_\_\_\_\_ (*what*)

\_\_\_\_\_ (*how much*)

\_\_\_\_\_ (*when*)

\_\_\_\_\_ (*how many?*)

How confident are you that you can complete this action plan?

\_\_\_\_\_

Not at all											Totally
confident	1	2	3	4	5	6	7	8	9	10	confident

Keep a record of how you did:

	I Plan to.....	I did.....
<b>Monday</b>		
<b>Tuesday</b>		
<b>Wednesday</b>		
<b>Thursday</b>		
<b>Friday</b>		
<b>Saturday</b>		
<b>Sunday</b>		

# Exercise Diary

Use this exercise diary to keep track of your exercise goals and activities.

Start off by writing down your goal.

Write down here what you want to be able to do: \_\_\_\_\_

Now, what do you want to be able to do this week which will help you to reach your goal?

Remember from your action plan to include:

*What* you want to do

*How much* you are going to do

*When* you are going to do it

*How many* days a week you are going to do it



For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

\_\_\_\_\_ (*what*)

\_\_\_\_\_ (*how much*)

\_\_\_\_\_ (*when*)

\_\_\_\_\_ (*how many?*)

	<b>Exercise Planned</b>	<b>Exercise I did...</b>	<b>How did I feel? Do you need to change anything?</b>
<b>e.g.</b>	<i>20 mins in a.m. after breakfast and in p.m. after supper</i>		<i>Very tired by the second session, I'm going to cut it down to morning only for this week.</i>
<b>Monday</b>			
<b>Tuesday</b>			
<b>Wednesday</b>			
<b>Thursday</b>			
<b>Friday</b>			

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## Week 4: Pain

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Many people living with HIV/AIDS experience pain and it is very often the symptom which bothers them most. We know this from lots of scientific studies conducted across South Africa, Africa and the rest of the world. There can be many reasons for someone living with HIV/AIDS to have pain. The pain may be caused by the virus, or the pain may be caused by the medicines used to keep you healthy or the pain might be for a reason that has nothing to do with HIV/AIDS.



The pain may be caused by the disease, for example if the virus damages nerves you may feel pain. Pain may also be caused or made worse by tense muscles. When something hurts we tend to make our muscles tense to try and protect ourselves. Pain may also be caused by weak muscles or stiff joints. People with HIV/AIDS often become less active and their muscles and joints get weak and stiff. Then when they do use their muscles and joints these can hurt because they haven't been used for a long time and they aren't used to it. Finally stress, fear, anxiety and depression can cause pain and make pain



worse. We know from research that when you are in pain your brain is very active. If you are also stressed, or afraid, worried or anxious, or depressed, your brain becomes even more active. This does not mean that your pain is not real, what it does mean is that activity in your brain can cause pain or if you are already in pain, it can make it worse.

To properly treat pain we have to make sure that we check and treat all the possible causes of pain.

### Checking the cause of pain

If you develop a new pain which you have not felt before it is important for you to pay attention to it. Pain is your body's way of getting your attention that something might be wrong. It does not always mean that something is wrong; it may just be a warning. It's like when you put your hand on something hot, it hurts and you pull your hand away. Often your hand is not burnt, but it was painful, the pain got your attention quickly and you moved your hand before you got burnt.

If you have not felt the pain before it is important for a doctor or a nurse to examine you to find the cause of the pain. If they find the cause of the pain they may give you medication to treat the cause. If you have TB you might have pain, the doctors or nurses might give you medicine for the TB to treat the cause of the pain. They should also give you medicine for the pain itself. If they forget to give you pain medicine you must ask for it. Sometimes you may only be given pain tablets for a few days, if you know your pain lasts for



the whole month you must tell the nurse or doctor this and they should give you medicine for the whole month.

In up to one third of people with HIV/AIDS who have pain, the doctors or nurses might not find any reason or cause for the pain. This does not mean that the pain is not real or that it should not be treated. If they do not find a clear cause for your pain they should still give you pain medicine.

### What can you do for pain?

There are lots of things you can do for yourself to help manage your pain. Because we know that the brain is very involved when someone is in pain, we also know that understanding your illness, being a self-manager who understands about their treatment and, having support can help manage your pain. We are now going to talk about different things that you can do to help decrease pain.

#### **Exercise**

Doing any kind of exercise, stretching, strengthening or endurance exercise can all help to decrease pain. We also know that people who exercise regularly have less pain.

#### **Relaxation**

Managing stress and doing relaxation exercises also helps to decrease pain. This works because it decreases the activity in the brain. We also know that if you do regular relaxation it can help you to sleep better. People with pain often find that the pain is worse at night and that it is difficult to sleep. Bad sleep can also make pain worse. Doing relaxation and being able to sleep better will help to reduce the pain and help to prevent it getting worse. You can also help your pain by managing stress and anxiety. You can do this by talking to people and getting support, either from a nurse, a counsellor or a support group.



#### **Heat**

If your pain is being caused by tense muscles then heat can help to decrease it. You can warm up the muscles by having a warm bath or shower with the water on the affected area. If you cannot have a hot bath or shower, then keeping the muscles warm with clothes or a blanket can also help. There is one time when you should not use heat for pain. If you touch the painful area and it is already hot, this means it is inflamed and you should not make it hotter. If the area is infected or the skin is damaged then it is also better not to make it hot. In both these situations, it is better to use cold.

### **Cold**



Cold is a very good way to treat pain. When we make nerves that send messages warning us about damage cold, they slow down and send fewer messages. This means that we feel less pain. If you have a freezer then you could use a packet of ice or of frozen vegetables on the painful area. Only leave it on your skin for 10 minutes at a time. If you do not have a freezer then putting a damp cloth on your skin (if you have a fridge then use water from the fridge) will also work well.

### **Massage**

Self-massage is a very simple but very good way to treat pain. You may have even been doing it without realising this is what you were doing. If you have ever rubbed a painful arm or leg then you have done some self-massage. You can use a simple cream or baby powder to do massage. Gentle rubbing of a painful area can relieve pain a lot. BUT, as with heat, if the painful area is hot or infected then it is better not to rub it. Rather use cold. If you have pain *and* the painful area is hot, red and swollen this may be a sign of an infection. If you have been using ice on this for a day and it is not getting better, visit the clinic.

### **Support**

As we said before, when we feel pain, our brains become very busy. We often worry about the pain, we may feel scared about what is causing the pain or what the pain means (we often talk about this as stress – “I feel so stressed!”). We might wonder what we have done to be getting pain. The fear and worry we feel when we have pain can make the pain worse. This is why support is so important to help pain. It is helpful to talk to people that we trust about how we feel. It is also helpful to be reassured by a nurse or doctor about what is causing our pain. It may be that worrying about HIV is making your muscles tense and this is causing your neck to pain or causing headaches. It helps if the doctor or nurse can reassure you that the pain is caused by stress. This does not mean that you are making it up or that it is not real! It means that there is something you can do to help the pain. Talking to people, doing exercise and relaxation all help to manage stress and this will help the pain.



### **Medicine**

If you have medicine to help your pain it is important that you take it regularly. Do not wait for the pain to start before you take the medicine, if you wait it will not work as well. If the doctor or nurse has told you to take the medicine several times a day then it is important that you do this, even if you are not feeling any pain at the time; not feeling pain means that the medicine is working. Do not wait for the pain to come back again before taking another pill, it won't work as well.

If your medicines are not helping the pain then you must go back to the nurse or doctor. You might need stronger medicine or you might need to take two different kinds of medicine at the same time.

Common medicines used to treat pain are:

- Paracetamol (panado, dolorol, painamol, painstop) is a very good, very effective and safe medicine for pain. It is important not to take more than 10 tablets per day.
- Aspirin (disprin) is also very good but some people need to be careful with this medicine. If you use it for a long time you need to be careful of side-effects like ulcers, asthma or kidney problems.
- Anti-inflammatories like indomethacin (indocid), diclofenac (voltaren or panamor) or ibuprofen (brufen or inza) are good if your pain is being caused by inflamed muscles or joints. These must be taken with food. These can also cause side-effects like ulcers.
- Paracetamol and Codeine is stronger than paracetamol on its own. If you have been using paracetamol on its own and taking it as the nurse or doctor told you but your pain is not getting better they may give you paracetamol with codeine.
- Dextropropoxyphene (Doloxene) is a stronger pain medicine. This medicine is not easily available at clinics and the doctor or nurse would need to arrange for you to get it.
- Codeine phosphate is much stronger and can only be prescribed by a doctor. This medicine can make you sleepy and can cause constipation.
- Morphine is the strongest pain medicine. It can be taken up to 5 times a day. It also has to be prescribed by a doctor. If you are prescribed morphine make sure the doctor also gives you a laxative to prevent constipation.



Remember that the most important thing about the pain medicines is to take them before the pain starts or as soon as the pain starts. Don't wait for the pain to become severe before you take the pain medicine. It won't work nearly as well.

### **Pain**

- Pain is one of the most common symptoms people living with HIV/AIDS experience
- Pain can be caused by the virus, by tense muscles, by weak muscles and stiff joints.
- Pain can be caused by and made worse by stress and worry
- Exercise, relaxation, cold, heat and massage are all good ways of treating pain
- Medication for pain works best if it is taken regularly and before the pain becomes very bad.

## Action Plan Form - Pain

Think about one pain which you commonly experience. Use this action plan form to develop a plan of how you are going to manage that pain.

Be sure your action plan includes:

*What* you want to do

*How much* you are going to do

*When* you are going to do it

*How many* days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

	<i>(what)</i>
	<i>(how much)</i>
	<i>(when)</i>
	<i>(how many?)</i>

How confident are you that you can complete this action plan?

_____
Not at all                     Totally confident 1 2 3 4 5 6 7 8 9 10 confident

Keep a record of how you did:

	When I have pain I plan to.....	I did.....
<b>Monday</b>		
<b>Tuesday</b>		
<b>Wednesday</b>		
<b>Thursday</b>		
<b>Friday</b>		
<b>Saturday</b>		
<b>Sunday</b>		

# Exercise Diary

Use this exercise diary to keep track of your progress with your exercise goal which you set in week one.

Start off by writing down your goal.

Write down here what you want to be able to do: \_\_\_\_\_

Now, what do you want to be able to do this week which will help you to reach your goal?

Remember from your action plan to include:

*What* you want to do

*How much* you are going to do

*When* you are going to do it

*How many* days a week you are going to do it



For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

\_\_\_\_\_ (*what*)

\_\_\_\_\_ (*how much*)

\_\_\_\_\_ (*when*)

\_\_\_\_\_ (*how many?*)

	<b>Exercise Planned</b>	<b>Exercise I did...</b>	<b>How did I feel? Do you need to change anything?</b>
<b>e.g.</b>	<i>20 mins in a.m. after breakfast and in p.m. after supper</i>		<i>Very tired by the second session, I'm going to cut it down to morning only for this week.</i>
<b>Monday</b>			
<b>Tuesday</b>			
<b>Wednesday</b>			
<b>Thursday</b>			
<b>Friday</b>			

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## Week 5: Eating Well

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Eating well is important for everyone, eating well helps keep you healthy and if you are sick, either with HIV or any other illness, eating well is important to help you feel better. Treatment is not just taking anti-retroviral medicines; it is taking anti-retroviral medicines and eating well. When you are living with HIV, your body burns more energy than someone who does not have the virus. The virus makes your body use 10% more energy even when you are feeling well and between 20% and 30% more energy when you are feeling sick. This means that you have to eat more just to keep your weight the same. Losing weight is one of the most common symptoms of HIV. People with HIV mostly lose muscle weight, which makes them thin and also makes them weaker. So, how do you stop losing weight, or if you have already lost weight, how do you help your body recover? It is not difficult or complicated to eat well to stay healthy. We are going to discuss some simple steps to follow to eat well.



### What should I eat?

Our bodies need energy to be able to do all the things we need to do every day. This energy comes from food and the best source of energy is food which has complex sugars in it. Complex sugars are not sweet, they are foods that many of us eat every day – the starch foods. Starchy foods like bread, pap, rice, potato and mngqusho are high energy foods (complex sugars). When our bodies run out of this high energy food, it will start to use energy stored in the body. Before you had HIV, your body would use fat to provide energy. But, now with the virus your body uses energy stored in muscles – protein energy. If you do not eat enough, your body will run out of complex sugars to give it energy and will start using protein from the muscles. This means that you will start to lose muscle and not fat – we call this wasting. If you eat foods with complex sugars (starchy foods - energy foods) regularly you can stop this happening. If you have already lost weight because of the virus, then you need to eat food with protein to help your muscles recover. Try to make sure you have high energy food (starchy food) with every meal.



One of the important steps for eating well is to eat small meals or snacks often through the day. It is best to try and eat 3 meals a day and have another 2 snacks a day. This means that we should eat 5 times a day; these meals do not all need to be big meals, a snack might be some fruit, nuts or sour milk. By eating 5 times a day we can make sure that we do not run out of energy. When we run out of energy, our bodies have to work harder, if we have pain the pain will get worse, if we are tired we will become more tired, if we are feeling sad we will feel sadder when we

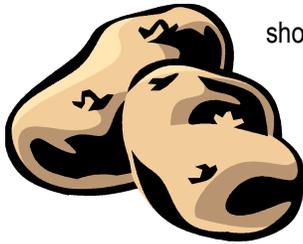
run out of energy and if you are trying to concentrate then it is harder to concentrate when you run out of energy. Also, if you have HIV and you run out of energy your body starts to use the protein in muscle and you start to develop wasting. For these reasons it is important to eat at least 3 times a day and better to eat 5 times a day.

There is no single food which is good or bad. It is important to eat a variety of foods. We will now talk about the different food groups which we should be eating from every day.

### Starchy Foods (also called carbohydrates or complex sugars)

*Bread-Potatoes-Pasta-Rice-Sweet Potatoes -Samp-Mealies-Sorghum-Pap-Porridge-Cereals*

We need to have enough energy, so the starchy foods (complex sugars) should be the main part of our diets. Starchy foods should make up the main portion of all meals. Starchy foods can give us energy for a long time. In the



shops or in magazines you might see food labelled “low GI”. “Low GI” foods are starchy foods which give us energy for a very long time compared to other starchy foods which are “high GI” which don’t give energy for as long. Both these kinds of starchy food are important for people living with HIV.

### Fruits and Vegetables

*Spinach-Morogo-Pumpkin-Green Peppers-Lettuce-Beans-Squash-Carrots-Tomatoes*

*Peaches-Apricots-Oranges-Naartjies-Avocados-Paw Paw-Mango-Guavas-Watermelon*

The second most important groups of food which we need are the fruits and vegetables. We should eat at least one fruit and one vegetable with every meal and aim to have at least 7 portions of fruits and vegetables every day. Fruits and vegetables supply vitamins and substances which are important for keeping the immune system strong. Try to eat a

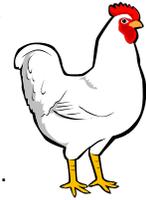


variety of fruits and vegetables and include vegetables which are yellow, orange, red or dark green in colour. These fruits and vegetables contain a vitamin (vitamin A) which helps the lining of the stomach. Citrus fruits like oranges, lemons, grapefruit and naartjies are also important as they contain another vitamin (vitamin C) which helps the immune system to work. You can see in the picture below that the starchy foods and fruits and vegetables are the biggest sections of food.

## Protein

*Beef-Pork-Chicken-Fish-Mutton-Lamb-Eggs-Milk products-Beans-Grains-Nuts*

People living with HIV need to eat protein every day. As we said before, this is important for your muscles and to help prevent weight loss. Protein is found in meats and milk based foods. You can also get protein from dried beans, peas, lentils, peanuts or soya. These foods can be a very economical way of getting enough protein, they are often much cheaper than meat or milk products.



## Fats and oils

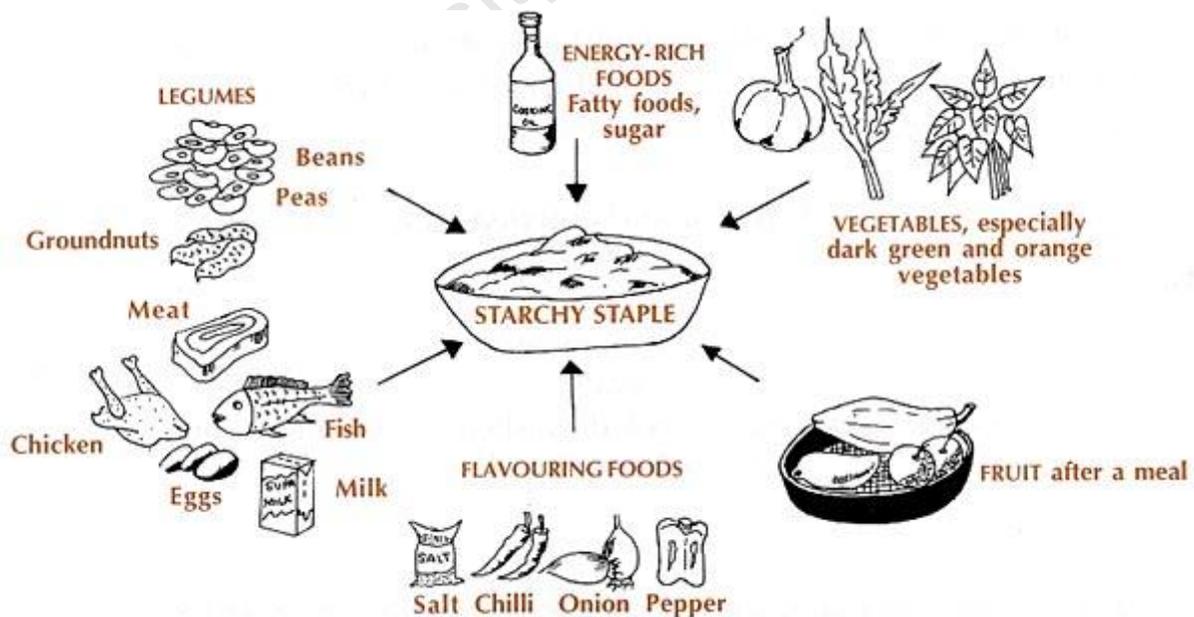
*Butter-Lard-Margarine-Cooking oils-Cream-Mayonnaise*

Fats and oils are also an important part of a healthy diet. These foods provide energy, like the starchy foods. This does not mean you can eat as much as you like of these foods, but they should make up a portion of your diet. These foods can be used to increase your weight if you have been sick with an infection and lost weight.



## How do I put it all together?

A balanced way of eating is for each meal to include two portions of starch + one portion of vegetables + one portion of fruit + one portion of protein. The fat portion of the food is included as part of the cooking (if you use oil) or if you put butter or oil on your food.



## A balanced meal

### **“I find it hard to eat well!”**

Now that you know what you should be eating let's talk about why people living with HIV may be struggling to eat enough. The reasons for not eating enough could be that they do not want to eat because they just don't feel hungry or because they are too tired to eat or they are too worried to eat or they feel like they will vomit if they eat, or they have diarrhoea or they have sores in their mouth which hurt when they eat or food just doesn't taste good any more. The next section gives ideas on ways to manage these problems.

### ***“I'm not hungry”***

On the days when you feel like eating, make sure you eat well to make up for days when you might not be eating so well. On the days when you do not feel like eating try to eat small meals more often, maybe 6 times a day. Eat in a relaxing place, maybe with a friend. Keep small snacks with you in your bag or next to your bed so that if you wake up or suddenly feel hungry you can eat straight away. Make sure these snacks have lots of energy in them (are complex sugars). Make sure you have your favourite foods to eat, even if it's just a little bit it helps.

### ***“I get full too quickly”***

You might be trying to get all your food at one meal. Try to eat five or six times a day. When you do eat, make sure its food with lots of energy and protein. Don't eat foods without energy first and then feel too full for important foods.

### ***“Food doesn't taste so good”***

Infections in the mouth or medicines can change the way food tastes. Sometimes you may have a bitter taste or a taste of metal in your mouth. If you have thrush, ask your doctor for medicine for this. You can also rinse your mouth with a mixture of 1 teaspoon of baking soda in a glass of water. DO NOT swallow this, rinse your mouth and spit it out. Try cleaning your teeth and your tongue before you eat. If you have a taste of metal in your mouth, try to drink orange juice or another tart drink.



### ***“Eating makes me want to vomit”***

Wanting to vomit when you eat can be because of an infection or a side effect of the medication. Eating smaller meals helps (5 or 6 meals a day) – it is important to know that nausea or the feeling that you are going to vomit is often worse when your stomach is empty. Food with lots of spices or fats and food or drink with caffeine can irritate your stomach and make you feel sick. Salty and dry food might help (bread or crackers). If the smell of food makes you feel sick, ask someone else to cook, and also make sure there is lots of fresh air where the cooking is being done so that the smell clears quickly. Don't eat your favourite foods when you feel sick, you don't want to start thinking that your favourite foods make you feel sick. If you think your medicine is making you feel sick, ask your

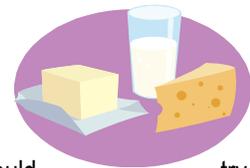
doctor or pharmacist about the best time to take the medicines which might help. You can also ask your doctor for medicine which will help to stop the feeling of nausea.

### *“I have diarrhoea”*

Diarrhoea can be caused by the virus, by the medicines or by stress or other infections. When you have diarrhoea, your body is not getting the food that it needs, even if you are eating it, your body cannot absorb it. When you have diarrhoea, your body is also not getting enough fluids. You need to make sure you are getting enough liquid when you have diarrhoea to make sure that you don't get dehydrated. Go to the section on managing symptoms of HIV/AIDS for more information on how to manage diarrhoea. Remember, if you have diarrhoea for more than a week, you must go to your clinic for treatment.

### *“I feel sick if I eat dairy products”*

Some people living with HIV find that drinking milk or eating milk products makes them feel sick. This is because the virus can affect a chemical in your intestine which you need to absorb milk. If this chemical is not present, you may feel bloated or get diarrhoea after eating milk products. This is called lactose intolerance. If this is happening to you, then you need to avoid eating milk products. Sometimes this reaction will get better; you might find that in a few months you could try a milk product again and not have the same reaction. This would mean that your body now has enough of the chemical it needs and you can resume eating milk products.



### *“My mouth is dry / I have sores in my mouth / chewing and swallowing hurts”*

A dry mouth might be a side effect of medications. Sores and pain in the mouth can be from infections. You can help this by avoiding smoking and drinking alcohol as these irritate your mouth and throat. Eat softer food, if you mash your food or make soup as this will be easier to swallow. Try not to eat food with a lot of spices or drink fizzy drinks if your mouth is sore. These can make your mouth burn more. Eating cold food like ice cream or sucking on an ice block can help to numb your mouth. If your mouth is sore, try to drink through a straw. Rinse your mouth often and keep a bottle of water next to your bed so that you can rinse your mouth during the night.

#### **Managing Eating Problems**

- Try to eat at least 5 times a day – 3 meals and 2 snacks.
- Eat energy food first.
- Keep snacks with you to eat as soon as you feel hungry.
- Drink 6 glasses of juice and water a day.
- Drink rehydration fluid after every bout of diarrhoea.

Now that we have discussed how we should be eating and ways of managing eating problems, let's look at how to keep our food safe.

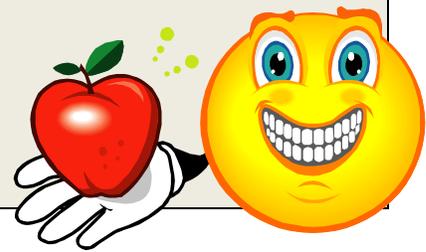
### How do I keep my food safe?

If we don't pay attention to our food, where we get it from, how we store it and how we prepare and cook it, the food may become contaminated and make us sick. This is very important for the person living with HIV because you are more vulnerable to illness. There are simple ways to keep your food safe.



#### **Storing and preparing food safely**

- Read food labels carefully when you are shopping for food. Look for the “sell-by” and the “use-by” dates. Do not buy them if the “sell-by” date has already passed, do not buy if you are not sure that you will eat it before the “use-by” date.
- Don't buy food if the packaging is damaged
- Storing food properly is important to keep it safe. Food that you buy from the fridge or freezer section of a shop needs to be put into a fridge or freezer as soon as possible unless you are going to cook or eat it straight away.
- Write on the packages of food the date you bought them so that you can keep track of how long you have had it. Remember food that can make you sick doesn't always look or smell bad.
- If you want to keep leftover food, store it in a container with a tight lid and put it into a fridge or freezer immediately.
- If you have leftovers in the fridge you must eat them within 2 days. Leftovers that have been in the fridge for more than 2 days MUST be thrown away - even if they look and smell OK!
- Always wash your hands before preparing food. Wash your hands again after handling any raw food.
- Wash up all your cutlery and crockery in HOT soapy water.
- If you have eaten food that has made you sick it is important that you clean all equipment and surfaces in the kitchen which that food might have touched. You can clean it using a mixture of 1 tablespoon of bleach in a litre of water.
- Never eat raw meat, chicken or fish of any kind.
- Make sure all meat is well cooked – no red meat of any kind.
- When you buy eggs make sure none have cracked shells. Keep them cold
- Never eat any dish with raw eggs
- Use only pasteurized milk and milk products
- Wash all fruit and vegetables
- Keep fruit and vegetables in the fridge



# Action Plan Form

Think about your eating habits. Use this form to come up with a plan to improve **one** thing about your nutrition.

Be sure your action plan includes:

*What* you want to do

*How much* you are going to do

*When* you are going to do it

*How many* days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

\_\_\_\_\_ (*what*)  
 \_\_\_\_\_ (*how much*)  
 \_\_\_\_\_ (*when*)  
 \_\_\_\_\_ (*how many?*)

How confident are you that you can complete this action plan?

\_\_\_\_\_

Not at all												Totally
confident	1	2	3	4	5	6	7	8	9	10	10	confident

Keep a record of how you did:

	I Plan to.....	I did.....
<b>Monday</b>		
<b>Tuesday</b>		
<b>Wednesday</b>		
<b>Thursday</b>		
<b>Friday</b>		
<b>Saturday</b>		
<b>Sunday</b>		

# Exercise Diary

Keep using the exercise diary to keep track of your exercise goals from week one. You may want to start increasing your exercise plan.

Start off by writing down your goal.

Write down here what you want to be able to do: \_\_\_\_\_

Now, what do you want to be able to do this week which will help you to reach your goal?

Remember from your action plan to include:

*What* you want to do

*How much* you are going to do

*When* you are going to do it

*How many* days a week you are going to do it



For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

\_\_\_\_\_ (*what*)

\_\_\_\_\_ (*how much*)

\_\_\_\_\_ (*when*)

\_\_\_\_\_ (*how many?*)

	<b>Exercise Planned</b>	<b>Exercise I did...</b>	<b>How did I feel? Do you need to change anything?</b>
<b>e.g.</b>	<i>20 mins in a.m. after breakfast and in p.m. after supper</i>		<i>Very tired by the second session, I'm going to cut it down to morning only for this week.</i>
<b>Monday</b>			
<b>Tuesday</b>			
<b>Wednesday</b>			
<b>Thursday</b>			
<b>Friday</b>			

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## Week 6: Continuing as a Successful Self-Manager

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Over the last six weeks you have learnt many skills which will help you to live positively with your condition. Research tells us that people living with any chronic disease who follow these steps have better quality of life, have fewer sick days and have better disease control. This is true for people living with high blood pressure, HIV/AIDS, cancer or depression. You have learnt how to be a positive self-manager by being able to solve problems and set goals for yourself so that you can move forward with your life. You have learnt about the importance of exercise. How exercise can make you feel better, what exercises you should do and you have been doing those exercises too! You have learnt about the common symptoms that trouble people living with HIV and you have learnt how to manage these symptoms. You have learnt about pain, what might be causing pain and how to treat and manage any pain you may have. You have learnt about food and eating well and how to make sure that your food is safe. With all of these you have also had the chance to practice doing things differently and to think about how this has made you feel.

### Action Planning for the Future

Now it is time to think about the future. People with long term illnesses often worry about what will happen if they get very sick, how they will manage their lives; how they will they look after themselves or their families. Worrying about these things can also make people feel sad, angry or depressed and helpless. These emotions may make everything feel even more difficult than they are. By working through this book you have already started to deal with these emotions. You have increased your knowledge and this is one of the main ways that we manage fear. If we are afraid of something, knowing more about it helps us to tackle the fear. If you know more about it, you can make a plan around it and making a plan helps us to get a sense of control over the very thing that we are afraid of.

Planning for the future means thinking about the things that might happen to you in the future and planning for them. You may never ever need to use the plan as the things that you worry about may not happen, but, having a plan will help you to worry less about these things and stay in control should they happen. You can use the action planning forms you have been using in this workbook to think about the things which worry you about the future. You can then start making a plan about what you want to do if these things happen. If you are not sure about making a plan, you may want to talk to different people who might be able to help you with this.



**Step 1:**

To be able to plan for the future, you need to decide *what* it is that you are worried about happening. This can be the hardest step to think about. For example you might be feeling very sad and depressed. First you need to think about why you are feeling that way. It might be that you are worried about not being able to look after your family if you become ill, or you may be worried about making someone else ill, or you may be worried about not being able to look after yourself, or you may be worried about dying. Once you have identified what it is that worries you and makes you feel sad, depressed, angry or afraid then you can start to make a plan to deal with it. This will help you to feel less sad, depressed, angry or afraid.

Write down here some of the things that might happen in the future that you worry about:

1) \_\_\_\_\_  
\_\_\_\_\_

2) \_\_\_\_\_  
\_\_\_\_\_



**Step 2:**

Now that you have identified some of the things which worry you, you can start to think about different ways to manage these things. If you were worried about becoming ill and not being able to look after yourself, write down a list of things that you would need help with. Then write down who you could ask to help you with those things. The people who can help might be family, friends, social workers, counsellors, nurses, physiotherapists, occupational therapists or doctors. If you are not sure who could help you, you may want to talk to someone you trust to help you identify who could help.

Write down here three different things you could do to help plan for the things in the future that you worry about:

1) \_\_\_\_\_

2) \_\_\_\_\_

3) \_\_\_\_\_

There are many organisations and people who you can approach for help in planning for the future. These organisations include the Treatment Action Campaign (TAC), the Family and Marriage Society of South Africa (FAMSA), your church, the AIDS consortium; the Aids Law Project (ALP), the National Association of People living with HIV/AIDS (NAPWA) as well as the health care practitioners at your local clinic. The contact details for these organisations are included at the end of this section.

Once you have completed Step 2 and written down three different things you could do to help plan for the things in the future that you worry about, choose the one which seems to suit you the best (this might be one which is easier or is cheaper or you know has worked for someone else). Now use this action plan form to work out what you will do if the thing which you worry about happening should happen. You can use this method to plan for any of the things which worry you.

Action Plan Form for Future Worries

I am worried that in the future I will not be able to:

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My plan to manage this if it happens is to:

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(what, who, how, when?)

How confident are you that you can complete this action plan? (remember you are aiming for 7 out of 10 on the confidence line)

Not at all										Totally	
confident	1	2	3	4	5	6	7	8	9	10	confident





### Useful Organisations:

Treatment Action Campaign (TAC) (<http://www.tac.org.za>)

Cape Town (021) 422-1700

Khayelitsha (021) 364-5489

Family and Marriage Society of South Africa (FAMSA) (<http://www.famsa.org.za>)

Cape Town (021) 447-7951

Khayelitsha (021) 361-9098

AIDS consortium (<http://www.aidsconsortium.org.za/>)

National office (011) 403-0265

Aids Law Project (ALP) (<http://alp.immedia.co.za/>)

National office (011) 356-4100

National Association of People living with HIV/AIDS (NAPWA) (<http://www.napwa.org.za/>)

Cape Town (021) 425-6860

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## Additional Reading

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The information in this workbook is based on several sources of information. If you would like to read more on any of these topics we suggest you explore these:

Living Well with HIV & AIDS; Gifford A.L.; Lorig K; Laurent D; Gonzalez V (3<sup>rd</sup> edition) Bull Publishing Company, Boulder Colorado 2005

Self-management of Long-term Health Conditions: A handbook for people with chronic disease. Expert Patients Programme Community Interest Company . Bull Publishing Company, Boulder Colorado 2007

Manage your pain. Nicholas M, Molloy A, Tonkin L, Beeston L ABC Books, Sydney 2000

HIV in our lives: a book of information sheets for clinics. Treatment Action Campaign, Cape Town, 2007

## Appendix H: Agreement of participation



### Agreement of Participation

I, \_\_\_\_\_ understand that all discussions which take place during these workshops are confidential. I agree to maintain the trust of those who are participating in the workshops with me.

I agree to attend all six (6) of the workshop sessions so that I can get the most benefit from them. If for any reason I am unable to attend I will inform the workshop facilitator (name, telephone number) or the researcher (Romy Parker 072-6586836) as soon as possible.

I understand that this course is aimed at teaching me how to live with a chronic disease. In order to develop the skills needed for this I understand that I will need to set goals on a weekly basis. I will share these goals with the group and share my progress in achieving them. I understand that this will be of benefit to me and others attending the group.

Signed \_\_\_\_\_

Date \_\_\_\_\_

# Appendix I: ACSM exercise screening

Telephonic screening for exercise using the ACSM screening guidelines:

1. As part of this study you will be asked to do exercises. I need to ask you some questions now to make sure that it will be safe for you to do these exercises. Can I ask you these questions now?

a. Do you have or have you had any of the following? (category 1 – immediate exclusion. Yes to any of these, stop the interview and thank them for their time. Afraid they are not eligible for the study)

A heart attack

Heart surgery

Cardiac catheterization

Coronary angioplasty (PTCA)

Pacemaker/implantable cardiac defibrillator/rhythm disturbance

Heart valve disease

Heart failure

Heart transplantation

Congenital heart disease

b. Screening question (see specific responses)

• Do you have diabetes?

IF YES, Is it controlled by medication? Yes – OK; No – end interview, thank you but not eligible

• Do you have asthma other lung disease?

IF YES, Is it controlled by medication? Yes – OK; No – end interview, thank you but not eligible

**YES to 2 or more of these 4 following questions not eligible, end interview, thank you for your time**

1.  Do you have burning or cramping in your lower legs when walking short distances.

2.  Do You experience chest discomfort with exertion.

3.  Do You experience unreasonable breathlessness.

4.  Do You experience dizziness, fainting, blackouts.

5. Are You are pregnant? Sorry but not eligible, thank you for your time

# **Appendix J: Intervention study information sheet and consent form**

## **WHAT ARE WE TRYING TO DO?**

I am a researcher from the University of Cape Town and I am interested in finding out whether a six week long course aimed at increasing your knowledge about HIV/AIDS and which includes exercise will make a difference to your health. I want to answer questions such as does increasing your knowledge of HIV affect the way in which people play a role in the family and take part in community activities? And does increasing your activity levels through exercise affect your health? In order to answer these questions we would like to interview people whom we know are HIV positive and invite them to commit to taking part in a six-week exercise and education course.

## **WHY HAVE WE CONTACTED YOU?**

We have contacted you because you took part in the survey last year and this course may be of benefit to you.

## **WHAT WILL YOU BE ASKED TO DO?**

As in the survey, the field worker, will interview you and fill in a questionnaire. This will find out more about whether you as a person who is HIV positive cope with the disease, and what things are difficult to do. This is the same questionnaire which you filled out previously and we will be repeating it to see if anything has changed.

Each interview will take about 30 minutes. We know that this is a long time but we want to get as much information as possible so that we can better understand the problems that you face.

After completing the questionnaire you will be randomly placed in one of two groups. Depending on which group you are put in you will then be asked to attend the Michael Mapongwana Physiotherapy department where the course will be run either on a weekly basis or once every four weeks.

If you are placed in the group for the course you will be asked to come to the centre once a week for six weeks for the course; in the fourth, eighth, twelfth and sixteenth weeks you will be asked to fill out the questionnaires again. The course will take place over 2 hours either on a Tuesday or Wednesday afternoon from 1pm to 3pm and will include gentle exercise as well as discussions on HIV, diet and other health related issues aimed at helping you cope with your disease.

If you are placed in the other group you will be given all the information in a booklet. You will then be asked to attend the physiotherapy department once every four weeks (weeks four, eight, twelve and sixteen) for four months so that we can see how you are doing.

We will want to stay in contact with you for four (4) months from the beginning to the end of this project so that we can see how you are doing over a period of time. In order for us to measure how you are doing we will ask you to complete the questionnaires again every month. To help us keep in contact with you we will ask you to give us a telephone number where you can be contacted.

### **WHAT WILL I GET IF I TAKE PART?**

There is no payment or reward for taking part in the study. We will be able to give you R20 to cover transport costs each time you visit the clinic for this study. We hope that you will learn more about HIV by doing the course and that this might help you to cope better with your illness. We will make all the information known (but of course not your name or address) to the local authorities, to the local institutions that provide assistance to people living with HIV/AIDS and to provincial and central government. We hope that what we find might lead to changes being made, but we cannot promise this. In the short term there will be no direct benefit to you or your family.

Nothing bad will happen to you if you do not want to take part. Even if you do take part, you can stop answering questions at any time and you can refuse to answer specific questions or you can stop attending the course if you wish to do so.

If you would like them to do so, the field assistants will refer people who take part to whatever services they need which may be available in the area.

### **WILL PEOPLE KNOW WHAT ANSWERS I HAVE GIVEN?**

All the answers will be put together and no-one will know who gave any specific answer except the researchers and maybe members of the Ethics Committee of the University of Cape Town (which is a committee that makes sure that people who take part in research are protected). Your name will not be given to anyone and will not be listed anywhere. The results of the project will be made available to organizations involved in assisting people living with HIV/AIDS, local and government authorities and the scientific community but no names will be linked to any results.

**Your participation is appreciated. Should you have any questions please contact Romy Parker at the University of Cape Town on (021) 4066431.**



**Department of Health and Rehabilitation Sciences**

**Faculty of Health Sciences**

Divisions of Communications Sciences and Disorders,  
Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital,

Observatory 7925

Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406 6323

Dear participant

Please read the attached information sheet.

We hope that this research will help health professionals to better understand whether a six-week course which includes exercise and education on HIV helps people to cope with being HIV positive. All questionnaires are anonymous and records will be kept strictly confidential.

You are welcome to contact the Investigator, Romy Parker at (021) 4066431 or, lecturer in Physiotherapy at the University of Cape Town for further details about the research and your rights. This research is voluntary and refusal to participate or decision to withdraw at any time will involve no penalty or loss of benefits to which you, the participant, are otherwise entitled.

I, \_\_\_\_\_ acknowledge that I have read and understand the above information and have willingly chosen to participate in the study. I know that I can withdraw at any time and that I do not have to answer all of the questions if I do not want to.

I give permission for the researchers to contact me to interview me. I agree to attend the course for six (6) weeks if I am placed in the course group, and I agree to be visit and take part in the study for a period of four (4) months.

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date

## Appendix K: Certificate of attendance

**CERTIFICATE OF  
ATTENDANCE**

This is to certify that

*Xxxx Xxxx*

Has attended the six-week course

**Positive Living**

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Held at Michael Mapongwana Physiotherapy  
Department from 23 August – 27 September 2011



Romy Parker

## Appendix L: Additional data from intervention study

Table L-1: Clinical characteristics of participants at baseline (15 months previous) (N=27)

	Participants		Experimental Group		Control Group		Significance Test
	Frequency (%)	Mean ± SD (Range)	Frequency (%)	Mean ± SD (Range)	Frequency (%)	Mean ± SD (Range)	
<b>CD4+ Count</b>	N = 25		n = 10		n = 15		
Most recent CD4+ count		332.52 ± 190.03 (100 - 751)		381.6 ± 202.19 (126 – 751)		299.8 ± 180.99 (100 - 714)	U = 53.5; p = 0.24
<b>Clinical Stage (I – IV):</b>	N = 27		n = 12		n = 15		
Stage I	4 (14.8)		1 (8.3)		3 (20)		$\chi^2 = 2.34$ ; p = 0.5
Stage II	4 (14.8)		1 (8.3)		3 (20)		
Stage III	10 (37)		6 (50)		4 (26)		
Stage IV	8 (29.6)		3 (25)		5 (33.3)		
Missing	0 (0)		1 (8.3)		0 (0)		
<b>Treatment:</b>	N = 27		n = 12		n = 15		
First Line ARVs	20 (76.9)		7 (76.5)		13 (72.2)		$\chi^2 = 3.29$ ; p = 0.07
Second Line ARVs	5 (19.2)		4 (12.5)		1 (0)		
Missing	1 (3.8)		1 (0)		0 (0)		
<b>Time of treatment</b>	N = 21		n = 9		n = 12		
Months since diagnosis		49.81 ± 38.26 (0 – 137)		51.6 ± 33.37 (7 – 95)		49 ± 41.8 (0 – 137)	U = 25; p = 0.82
Months since initiating treatment		22.65 ± 20.28 (0 – 66)		29.09 ± 23.17 (0 – 66)		18.44 ± 16.42 (0 – 54)	U = 40.5; p = 0.52

Table L-2: Opportunistic Infections at Phase I

	Participants (N = 27)		Experimental Group (n = 12)		Control Group (n = 15)		Significance Test
	Number	%	Number	%	Number	%	
<b>Tuberculosis</b>							$\chi^2= 4;$ $p = 0.41$
Extrapulmonary	2	7.4	1	8.3	1	6.7	
Pulmonary	2	7.4	1	8.3	1	6.7	
<b>Candidiasis</b>							
Oral	1	3.7	0	0	1	6.7	
<b>Genital Herpes</b>	1	3.7	1	8.3	0	0	

University of Cape Town

Table L-3: Pain; Self-efficacy, HRQoL, Depression, Childhood trauma and Adult trauma at Baseline and at Week 0

	Participants (N = 27)	Experimental Group (n = 12)	Control Group (n = 15)	Significance Test
	Mean ± SD (Range)	Mean ± SD (Range)	Mean ± SD (Range)	
<b>Pain</b>				
<b>Pain Severity Score</b>				
Baseline	5.32 ± 1.93 (2.25 – 9)	4.9 ± 1.85 (2.25 – 7.3)	5.67 ± 1.98 (3 – 9)	U = 68; p = 0.29
Week 0	5.55 ± 2.39 (2.75 – 9)	6.06 ± 1.19 (3.75 – 8)	5.13 ± 1.88 (2.75 – 9)	U = 59 p = 0.14
<b>Pain Interference Score</b>				
Baseline	6.3 ± 2.39 (2 – 10)	6.83 ± 2.26 (2.57 – 10)	5.87 ± 2.48 (2 – 9.86)	U = 66.5; p = 0.26
Week 0	6.39 ± 1.87 (3.57 – 10)	7.21 ± 2.15 (4.43 – 10)	5.73 ± 1.35 (3.57 – 7.71)	U = 52.5; p = 0.07
<b>Self-efficacy</b>				
Baseline	6.98 ± 1.54 (3.67 – 10)	7.22 ± 1.51 (3.67 – 10)	6.76 ± 1.58 (4.17 – 9.67)	U = 59; p = 0.14
Week 0	7.29 ± 1.32 (4.83 – 9.67)	7.21 ± 1.35 (4.83 – 9)	7.36 ± 1.33 (4.83 – 9.67)	U = 88.5; p = 0.96
<b>HRQoL</b>				
<b>EQ VAS</b>				
Baseline	66.66 ± 16.64 (30 – 90)	60 ± 11.28 (40 – 80)	72 ± 18.59 (30 – 90)	U = 48.5; p = 0.04*
Week 0	73.7 ± 19.64 (30 – 100)	70 ± 24.49 (30 – 100)	76.67 ± 14.96 (50 – 100)	U = 80; p = 0.64
<b>EQ-5D index</b>				
Baseline	0.61 ± 0.34 (-0.18 – 1)	0.53 ± 0.32 (-0.18 – 0.8)	0.67 ± 0.35 (-0.15 – 1)	U = 60.5; p = 0.16
Week 0	0.76 ± 0.22 (0.17 – 1)	0.71 ± 0.17 (0.26 – 1)	0.79 ± 0.25 (0.17 – 1)	U = 47.5; p = 0.04*
<b>Beck Depression Inventory</b>				
Baseline	19.81 ± 12.29 (2 – 51)	22.33 ± 13 (2 – 51)	17.8 ± 11.74 (2 – 43)	U = 69; p = 0.32
Week 0	14.93 ± 9.54 (1 – 37)	17.83 ± 12.08 (1 – 37)	12.6 ± 6.43 (1 – 23)	U = 68.5; p = 0.31
<b>CTQ</b>				
Baseline	50.11 ± 9.92 (38 – 69)	50.58 ± 10.28 (38 – 68)	48.93 ± 9.8 (38 – 69)	U = 74.5; p = 0.46
<b>Harvard Trauma Questionnaire</b>				
Total at baseline	1.78 ± 1.23 (0 – 3.4)	2.3 ± 1.06 (0 – 3.4)	1.36 ± 1.24 (0 – 3.4)	U = 49; P = 0.05*
PTSD at Baseline	1.87 ± 1.3 (0 – 3.63)	2.4 ± 1.09 (0 – 3.63)	1.46 ± 1.33 (0 – 3.63)	U = 53.5; P = 0.08

\*indicates significant difference between groups at p &lt; 0.05

Table L-4: Self-efficacy scores over time

	Participants (N = 27)	Experimental Group (n = 12)	Control Group (n = 15)
	Mean ± SD	Mean ± SD	Mean ± SD
<b>Baseline</b>	7.09 ± 1.58	7.57 ± 1.29	6.67 ± 1.73
<b>Week 0</b>	7.19 ± 1.31	7.15 ± 1.35	7.21 ± 1.32
<b>Week 4</b>	7.37 ± 1.63	7.67 ± 1.65	7.1 ± 1.64
<b>Week 8</b>	7.85 ± 1.31	7.76 ± 1.40	7.92 ± 1.27
<b>Week 12</b>	8.05 ± 1.36	8.02 ± 1.61	8.07 ± 1.2
<b>Week 16</b>	8.2 ± 1.38	7.86 ± 1.40	8.51 ± 1.36

Table L-5: Prevalence of Pain from Week 0 to Week 16

	Participants (N = 27)	Experimental Group (n = 12)	Control Group (n = 15)	Significance Test
	Frequency (%)	Frequency (%)	Frequency (%)	
<b>Week 0</b>				
Pain	27 (100)	12 (100)	15 (100)	
No Pain	0 (0)	0 (0)	0 (0)	
<b>Week 4</b>				$\chi^2 = 1.4$ ; $p = 0.71$
Pain	19 (70.4)	8 (66.7)	11 (73.3)	
No Pain	8 (29.6)	4 (33.3)	4 (26.7)	
<b>Week 8</b>				$\chi^2 = 2.22$ ; $p = 0.14$
Pain	16 (59.3)	9 (75)	7 (46.7)	
No Pain	11 (40.7)	3 (25)	8 (53.3)	
<b>Week 12</b>				$\chi^2 = 0.27$ ; $p = 0.60$
Pain	12 (44.4)	6 (50)	6 (40)	
No Pain	15 (55.6)	6 (50)	9 (60)	
<b>Week 16</b>				$\chi^2 = 2.7$ ; $p = 0.10$
Pain	9 (33.3)	6 (50)	3 (20)	
No Pain	18 (66.7)	6 (50)	12 (80)	

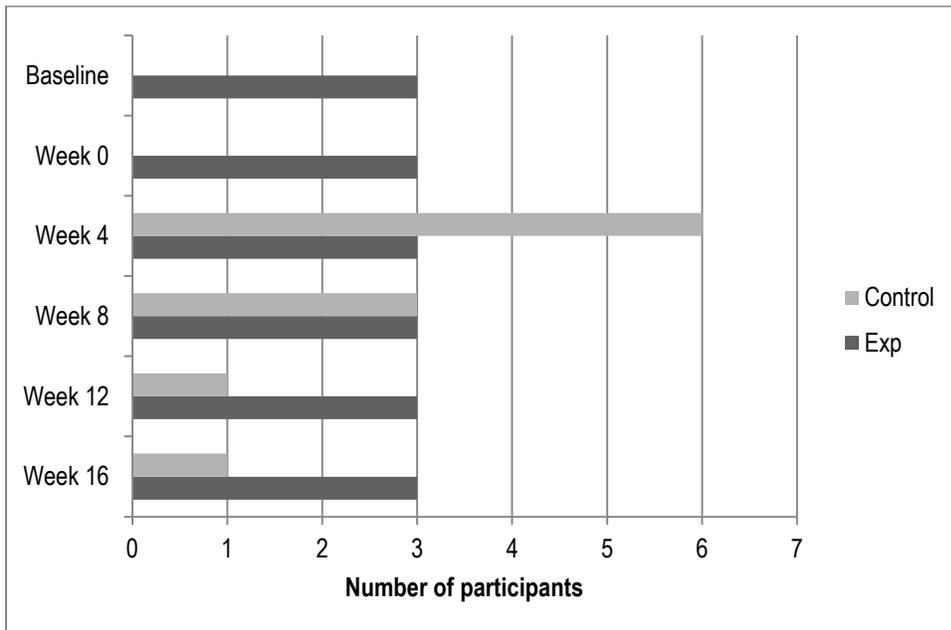


Figure L-1: Number participants reporting “Some problems” with mobility (N = 27)

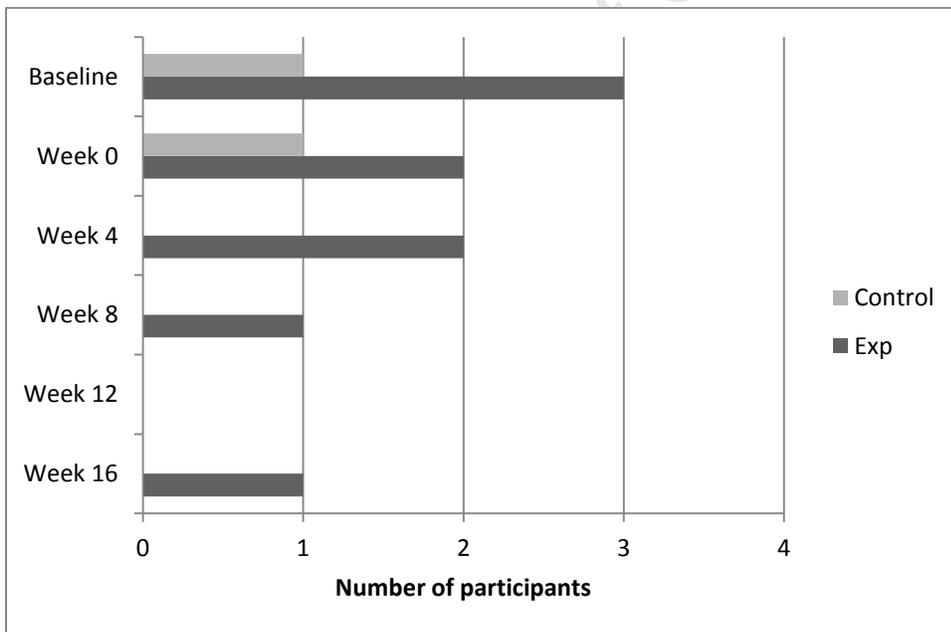


Figure L-2: Number of participants reporting “Some problems” with self-care (N = 27)

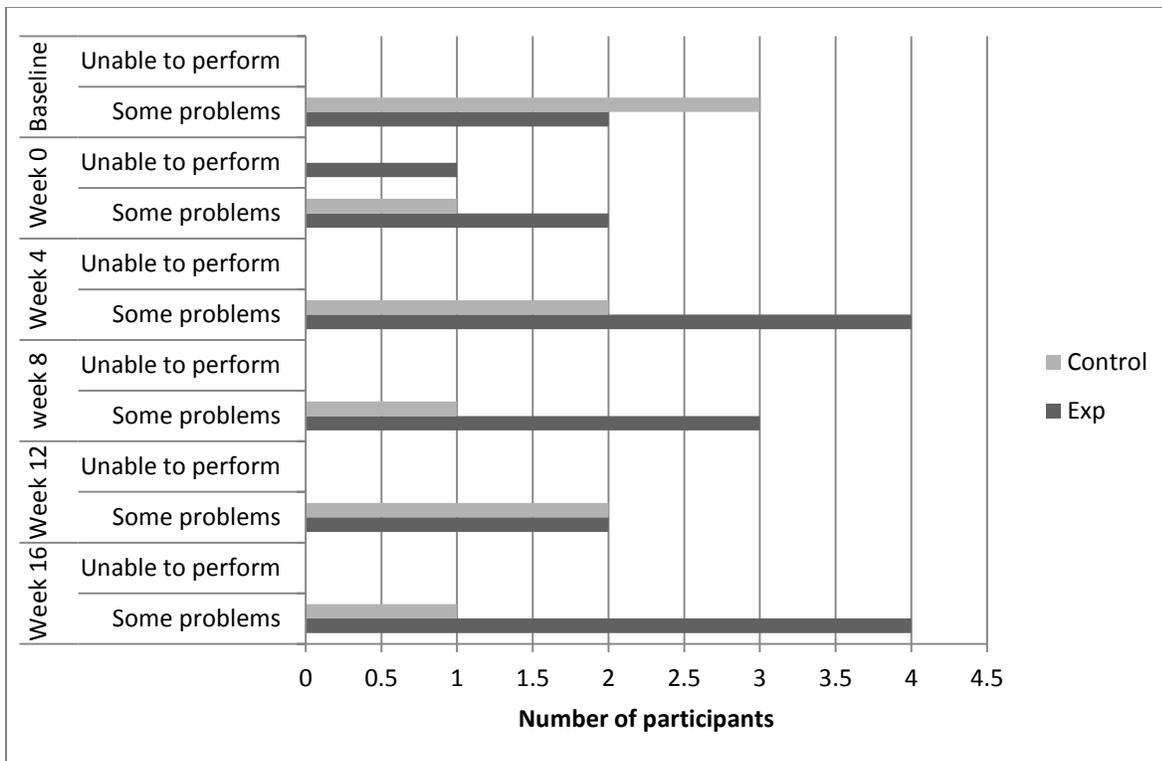


Figure L-3: Number of participants reporting problems with usual activities (N = 27)

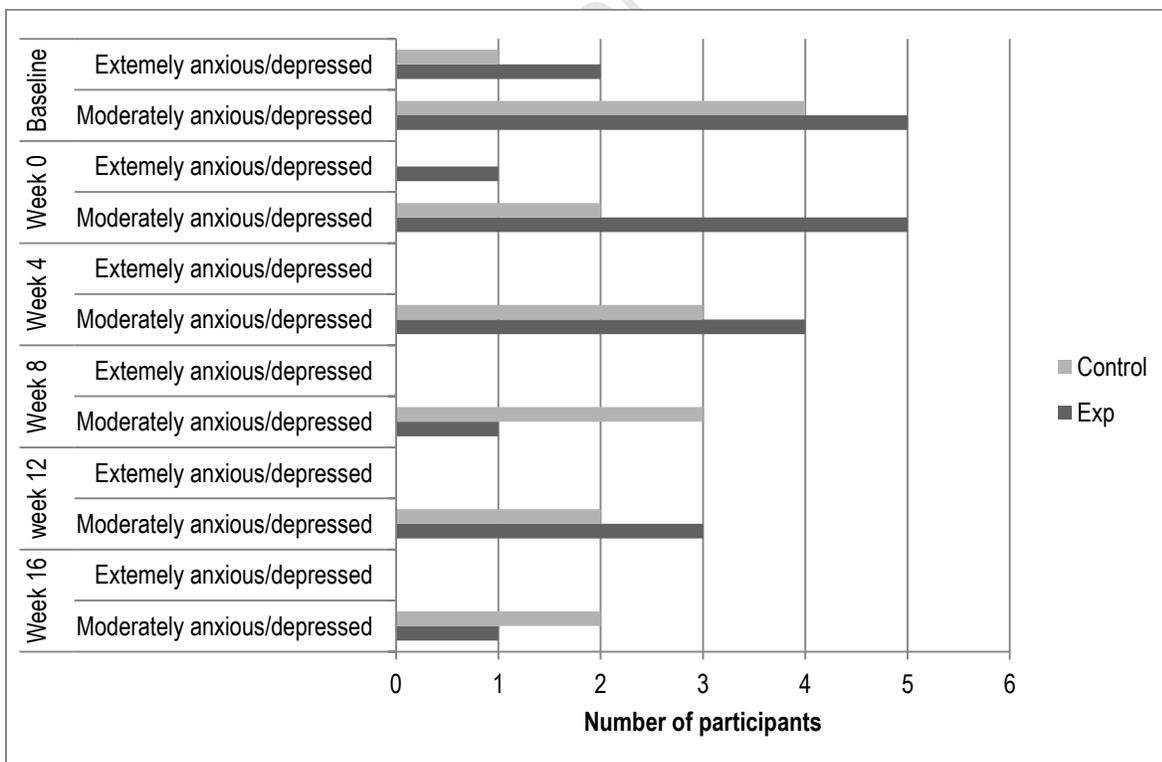


Figure L-4: Number of participants reporting anxiety/depression (N = 27)

Table L-6: Interview responses from the experimental group (n = 12)

Participant Number	What did you like about the course?
10	What I liked about the workshop I learnt a lot. I used to go to the clinic every time not feeling well, now I managed to exercise or drink water when I am not feeling well. Now I can talk to someone when I have a problem, is what I liked about the workshop.
12	Your book was so good in an amazing way. I mean I like it. It taught me a lot. I read everything, for example when I wanted to sleep I would take it and read it. At least there was a change brought in my life.
13	Something that I liked too much in this course is to work well with our manager, Romy Parker. The second thing our facilitator, we worked so well with her. So I learnt a lot because of her.
14	I like it because it taught me many things about HIV status. I like the exercise!
17	When I came here I thought it was a waste of...waste of time but I realised no, it is not because some things have helped my life.
18	What I like is that we were taught those things written in those books. I also liked the exercises. Should I mention one or all of them? Ok, I liked what we learnt in that book about HIV, the exercises and meeting new people here in the workshop. When we started she gave us a book to read and to do homework in it. We were often asked questions in it by Fumana
19	Yho Romy, I like your calls too much. Even my child is so interested; she gets so excited and asks me when we are meeting Romy again. I just think this child will make me not to forget about Romy and think about her always. We are talking about Romy. My child gets so excited and it excites me too. I learnt more. I like the way you work with people, you are always interested and if someone has a problem they can always come to you. So I liked your Study too much. (Phone ringing) I am sorry, just few minutes.
20	What I liked about the course is that we learnt a lot about things that we did not know, exercising and that we must eat healthy, e.g. veg and fruit, water. I have learnt that water is useful in everything, we should drink too much water and when you feel pain you do not have to run to the clinic you can drink water to see if we are going to be fine or not fine. If two days has passed, then you can now go to the clinic.
26	This workshop helped me a lot because I have learnt a lot.
30	What I liked is that it is easier to learn new things and it is easier to learn as a group. I have learnt how to behave and how to deal with problems. And the other thing, I got relieved and I was able to talk with people about my problems.
31	What I liked about this course it taught me a lot. Even the exercises that I was not doing, now I am doing them. Even my diet has changed for the better. I liked Romy's workshop so much. (Laughter)

<b>Participant Number</b>	<b>What did you like about the course?</b>
33	I liked the workshop because I have gained knowledge that I did not have. So I gained a lot because there were things that were putting me down in life but now I feel encouraged because I was attending. So I gained a lot.
<b>Participant Number</b>	<b>What didn't you like about the course?</b>
10	There is nothing I did not like, I liked everything. I enjoyed the workshop up to the end.
12	I like it Romy, very much
13	What I liked in the course the most is that the knowledge that I did not have about health and HIV AIDS that I am involved in. I have gained so much knowledge. Some things have shaped me so much. But because of this course conducted by UWC I have gained so much experience.
14	I like everything
17	There is nothing that I did not like. Something that I did not like before was exercise because I have never exercised before but now I can quickly feel a painful part in my body. Thank you
18	No, I liked everything
19	For me I like this course too much. I have so much interest in this course. I always think about you, thinking that it's been a while not seeing you. I like this course too much. I wish that you would continue with it not help only me but even other people.
20	No, there is nothing
26	There is nothing that I did not like. (Laughter) There is nothing that I did not like, everything was fine.
30	Its people who have gained knowledge in some certain areas but still not open up, people who were not participating in the workshop and people who were not attending. I could not participate also due to some issues.
31	No, there is nothing that I did not like about the workshop. Even if we can continue with it.
33	No, there is nothing I did not like. I liked the whole program

Participant Number	Was there anything more you would like to learn that wasn't in the course?
10	There is nothing that I want to add, instead I learnt a lot in the workshop. I wish everybody can come to the workshop to learn the way we have learnt. I was scared to talk about it before, but since I came to the workshop I realised that I am not the only one who is sick, there is many of us and we are living a normal life.
12	Yes, I was missing your book. It changed a lot of me. It change everything to me. I know a lot now about my... yes.
13	The truth is so far they have given us enough so far, other things will follow. I wish that more people could join in this course
14	I like it because it taught me everything about managing HIV and AIDS. (Laughter)
17	No, everything was fine. I did not expect to receive certificates when we attend the workshop. I thought it was just a workshop that we will attend and go home. Now we are going to show others that we attended this. So the was nothing wrong about this course, everything was perfect.
18	No there is nothing
19	Yho, I so interested in this course. I wish you could continue with it up to our children. I do not know what could happen if you cannot do this course, because it can be very helpful even to our children and show them it is not the end of life. I liked it so much Romy.
20	No, there is nothing
26	I would like it to continue. I am thinking if we can continue to sit down and talk about these things we can learn a lot.
30	I was thinking that people should bring their partners or people who are going to support them in this program. It is so much helpful, so that in what we learn we can share and not keep this knowledge to ourselves. Coming as groups was a right thing. I hope what we are learning it does not end here, so that even other people can get help.
31	No, there is nothing.
33	No

Table L-7: Interview Responses from the Control Group (n = 15)

<b>Participant Number</b>	<b>What did you like about the workbook?</b>
1	1 I have learnt something new I did not know about my life. How to take care of myself, that when I am sick I must not sit on the bed. I must always try to exercise. There is a lot that I have learned.
4	4 Okay, I am like it, everything there. Ja, because I'm- let's say I'm learning more about my... about Impilo.
8	8 What I like here is that they ask me about this sickness I have, my positive status and I feel proud about it. Since I started to know my status in 2001 I used to feel very bad when they talk about HIV on radio, but now I have become fine since I have joined support groups and places like these ones. I like to be around the people who are HIV positive like me. A person should know that they must take their tablets, ARVs, because they have to. Thank you.
9	9 What I liked about these books is that the knowledge I have, I share it with my neighbours, sit down with a cup of tea and share the knowledge. Maybe someone is sitting at home stressing and maybe she can't go somewhere else to relive her stress. Maybe if I can invite that person, talk to her maybe the stress can be revealed.
11	11 It gave me so much interest because now I have back my normal life. I am active as before because there are people who care for us who make us do these things so that we can be able to drink our tablets, ARVs. We get to realise that we are not alone; there are people who are supporting us.
21	21 I like the fact that it teaches on how to control my life. Now I can remain in health without any problems.
22	22 I liked it because it shaped me in my weight. I was exercising and it gave me tips on how to exercise. I think that's fine.
25	25 I like the fact that I can teach people because of these books. I can now exercise and so on through those books.
29	29 Ok, I liked it because it was encouraging me to exercise. I was able to remind myself that I should wake-up and think of exercising.
32	32 I like the way it is designed and the way it teaches us on what to do when we are upset. You should count things that make you happy and count things that make you unhappy so that you can prevent them.
35	35 Everything is fine. I do not have questions, I always leave well and they also give me taxi fare. Thank you for everything. Okay.
36	36 I like the part where it talks about exercises, on how can you exercise; when you are tired and having a headache. So I have learnt a lot.
<b>Participant Number</b>	<b>What didn't you like about the workbook?</b>
1	1 No, there is nothing
4	4 I like it
8	8 That I do not like? No, nothing
9	9 No
11	11 No
21	21 There is nothing I did not like. It teaches very well. Everything that I have learnt, it was good. Now I know how to conduct my life because I read that book.
22	22 Yes, you did not give us things to exercise. We also want things to exercise. (Laughter) One thing that I do not like is that they gave us big pamphlets and we can't read them because we are working.
25	25 No, there is nothing I did not like.
29	29 No, there is nothing I did not like

32	No, I liked it too much because it taught me a lot about taking care of myself.
35	Even if you cannot change anything, everything is fine. Next year I want more because I'm very happy.
36	No, there is nothing. I even read this book twice.
<b>Participant Number</b>	<b>Is there anything you would like to add or change in the workbook?</b>
1	What I like to know is that what you can do when you have something... I do not know. I do not have anybody that I can talk to when I have problems yet. I do not know who to talk to about these things here. I get confused. Things like I regret it when I have slept with someone without a condom. What should I say so that my partner should believe me? I get scared that if I can tell him he can do something bad to me. So I always need someone who can advise me.
4	Nothing at all. Nothing, nothing
8	No I do not see anything left out in the workbook. It seems as if they have covered everything for me and I am satisfied. Thank you.
9	No, everything is okay.
11	No there is nothing
21	Yes, I liked it very much
25	No, there is nothing
29	No, there is nothing I did not do or I should do. There is nothing.
32	No, it was okay for me. I mean I have learnt something that I did not know and about my rights.
36	No, I do not think there is something that was left out and that we were not thought about

