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A COMPARISON OF NON-PHARMACOLOGICAL INTERVENTIONS FOR REDUCING PAIN IN INDIVIDUALS WITH HIV.

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A Dissertation submitted to the Faculty of Health Science, University of Witwatersrand, in fulfillment of the requirements for the degree of Master of Science in Medicine.

Johannesburg, 2016

DECLARATION

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

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D Devan

09 Day of December 2016 in Johannesburg

ABSTRACT

HIV-related pain is commonly experienced by people living with HIV/AIDS; it compromises function and quality of life and there are no known effective pharmacological therapies. Previously, a peer led self-management group was no more effective in reducing pain and improving quality of life than controls who received an education book. Thus, the aim of this randomised single blinded study was to examine the effectiveness of three non-pharmacological interventions: a therapeutic relationship alone, a therapeutic relationship with education, and a therapeutic relationship with a peer led self-management group on pain and other variables. Forty-one HIV-positive participants aged 18 – 50 and currently receiving antiretroviral treatment, were recruited from the virology clinic of Charlotte Maxeke Johannesburg Academic Hospital. Participants were assessed at baseline and weeks 4,8,12 and 24. There were no significant changes in pain interference, self-efficacy, depressive symptoms or health-related quality of life either between the intervention groups or over time but there was a significant decrease in pain severity between the intervention groups. There were no changes in physical function between the groups but six components of physical function changed over time: loaded and unloaded reach, sit to stand and belt tie improved, preferred and fastest walking speed reduced. The study does not support the use of the therapeutic relationship, education or self-management for improving quality of life in HIV related pain, however, pain severity and physical function did change over time with the use of non-pharmacological interventions.

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LIST OF ABBREVIATIONS

PLWHA	People living with HIV/AIDS
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-retroviral
BPI	Brief Pain Inventory
BDI	Becks Depression Inventory
EQ5D	Euroqol 5D
SE6	Stanford Chronic disease 6 – item self-efficacy scale
IMMPACT	Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials
TENS	Transcutaneous Electrical Nerve Stimulation
CBT	Cognitive Behavioural Therapy
PLP	Positive Living Programme
CAM	Complementary and Alternative Medicine

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Chapter 1 Introduction and Literature Review

Introduction

Since the first cases of HIV were reported in the early 1980s, the HIV epidemic has spread globally. No region has been more affected than sub-Saharan Africa with 25.8 million people living with HIV/AIDS (PLWHA) in this region (UNAIDS; UNAIDS fact sheet 2015). As shown in Figure 1.1, more than 10% of the world's HIV infected population reside here (UNAIDS; UNAIDS Gap Report 2014. In this region, South Africa has one of the largest populations of people living with HIV/AIDS with 6.8 million being reported in 2013 (UNAIDS, UNAIDS South Africa 2013). The co-morbidities, associated symptoms and opportunistic infections that HIV brings with it, significantly affect the quality of life and function of those infected. This coupled with the level of poverty and lack of healthcare resources available in South Africa (Cobbing, Hanass-Hancock and Deane, 2014; Chetty and Hanass-Hancock 2016) make for a dire situation.

Pain has been reported as a symptom of HIV (Norval et al. 2004; Bhengu et al. 2011, Harding et al. 2011; Farrant et al.2012) and has been examined in PLWHA in terms of aetiology, prevalence and management (Frich and Borgbjerg 2000; Hitchcock et al. 2008; Aouizerat et al. 2010; Koeppe et al. 2010; Huggins et al. 2012; Maree, Dreyer Wright and Makua, 2013; Robbins, Chaiklang, and Supparatpinyo, 2013).Globally it is now agreed that the cause of the pain experienced by PLWHA is indeed varied, with the disease process, medication side effects, secondary complications, co-morbidities and unexplained aetiology often quoted as possible causes of pain in PLWHA according to literature reviews of HIV related pain (Marcus et al. 2000; Parker,Stein and Jelsma, 2014).

A quote taken from a study published in 2013 [''If only there was something that could be done.''] (Maree, Dreyer Wright and Makua 2013, p 99) suggests that the study participant believes that pain relief is not possible. This alludes to the possibility that pain management is inadequate in PLWHA. This is supported by findings of other studies which report inadequate treatment in this population (Narasimooloo, Naidoo and Gaede, 2011; Mphahlele, Mitchell and Kamerman, 2012; Farrant et al. 2012; Robbins, Chaiklang, and Supparatpinyo, 2013).

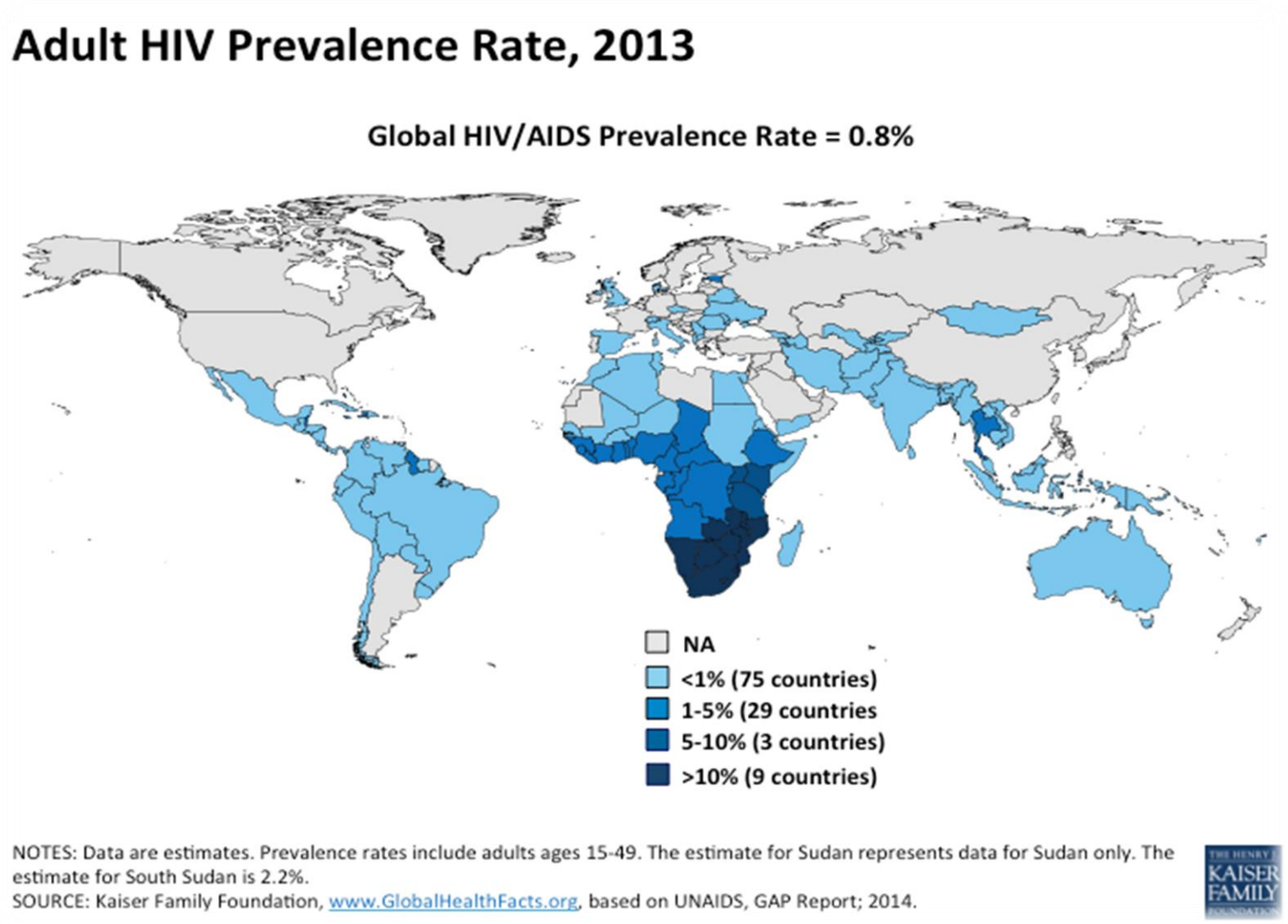

Figure 1.1 Adult HIV Prevalence Rate, 2013

This literature review will examine relevant research related to the experience of chronic pain in PLWHA including prevalence and associated risk factors, the physical and psychosocial impact of chronic pain as well as management strategies including pharmacological and non-pharmacological approaches.

1.1 Pain in HIV/AIDS

Unfortunately, one of the most common symptoms of PLWHA is pain, which is illustrated by a number of studies (Norval et al. 2004; Bhengu et al. 2011; Harding et al. 2011; Farrant et al. 2012; Peltzer K, 2013). The complaint of pain was the reason for the initial consult with a healthcare practitioner which led to the subsequent diagnosis of HIV in the study by Mphahlehle, Mitchell and Kamerman (2012). This was reiterated by Wahab and Salami (2011) who also reported pain on initial HIV diagnosis in their sample.

1.1.1 **Prevalence of pain in people living with HIV/AIDS**

In Table 1.1 studies done predominantly in the United States of America show a prevalence of pain of 22% to 91.8% (Frich and Borgbjerg 2000; Aouizerat et al. 2010; Harding et al. 2011; Miaskowski et al. 2011, Merlin et al. 2013; Robbins, Chaiklang, and Supparatpinyo, 2013). A high (91.8%) prevalence of pain was found in a community based sample of indigent or homeless people living with HIV/AIDS in San Fransciso (Miaskowski et al. 2011). The high prevalence of pain reported could have been influenced by the poor socioeconomic living conditions of this population. Table 1.2 shows a number of South African studies and one African study which also reflect a high prevalence of pain ranging from 27.8% to 91%. The study which reported 91% prevalence was, however, restricted to an inpatient population. The high prevalence of pain can therefore be attributed to the fact that all participants were ill at the time and the pain reported could have been due to other co-morbid illnesses or the reason for hospitalisation itself (Narasimooloo, Naidoo and Gaede, 2011).

Prevalence of pain noted in a rural cohort was higher than that of an urban cohort in the study by Mphahlehle, Mitchell and Kamerman (2012). There were several differences between these cohorts, the geographical location of where they resided, and possible cultural factors such as differing values and beliefs about HIV or pain and its management. The socioeconomic status and educational levels were similar in this cohort. Non-specific factors such as interaction with the researcher may have also played a role in the report of pain prevalence in this study (Mphahlehle, Mitchell and Kamerman, 2012). In contrast, a

Nigerian study found a lower prevalence of pain (27.8%) in an outpatient clinic population. The researchers attributed this to an acceptance that pain was a co-morbidity of HIV; therefore the participants may have felt that having pain was inevitable when one has HIV (Wahab and Salami, 2011). This may be a valid assumption, but would need to be proved by further research. The above studies demonstrate the variability of pain prevalence in PLWHA but also indicate that pain is a common symptom in PLWHA.

A systematic review by Parker,Stein and Jelsma (2014) reviewed data from studies with a total of 6814 individuals living with HIV/AIDS. The data were collected between 1993 and 2011 and the prevalence of pain ranged from 54% to 83% over a three month recall period. Pain intensity was reported to be moderate to severe and a moderate effect on function was found. This review supports the studies reviewed above and demonstrates the impact that pain has on PLWHA, as well as the high prevalence rates demonstrating that pain is commonly experienced by individuals with HIV/AIDS. It is important to note that this review included studies done in both high and low income countries and that the prevalence found was consistent over time and not affected by the advent of ARV's (Parker,Stein and Jelsma, 2014). This demonstrates that prevalence is not affected by socioeconomic status or use of ARV's.

1.1.2 **Intensity of pain in People living with HIV/AIDS**

International and South African studies reviewed reveal that the pain intensity experienced by people living with HIV/ AIDS most frequently ranges from moderate to severe. This is clearly shown by Table 1.1 and 1.2 where the mean pain intensity ranges from 5 to 8.2 in severity on a 10 point scale with 0 being no pain and 10 indicating severe pain. In the studies that did not report an average or mean pain intensity, the data were reported as falling into mild, moderate, or severe categories with the exception of Frich and Borgberg (2000) who described the pain intensity as disturbing. In this longitudinal study participants rated their pain intensity on a visual analogue scale according to mild, moderate or severe, however, the severity was reported as disturbing or not disturbing. This study also demonstrated a high pain prevalence. It is important to note that 79% of participants were in ill health and subsequently died by the time the last interview was conducted.The high incidence of ill health would then correlate with the high prevalence of disturbing pain found in their sample (Frich and Borgbjerg, 2000).

In a study, done by Mphahlehle, Mitchell and Kamerman (2015), it was interesting to note that the pain intensity decreased from a prevalence of 85% to 54% on follow up visits 6 months after the initial study. The researchers also found that 21% of those participants who experienced no pain at the initial visit, developed pain 6 months later and 20% of participants

with a moderate pain severity developed severe pain. It is worth noting that 40% of participants who reported pain initially had no pain at the 6 month follow up. These findings show that pain experienced by PLWHA may be unpredictable in nature. Reasons for the changes in prevalence and intensity remain unknown and is an area for future research.

Pain has been found to significantly affect function in other chronic pain populations including patients with cancer, chronic low back pain, arthritis and fibromyalgia (Kravitz et al. 2011; Gazzi Macedo et al. 2012; Dailey et al. 2013). The impact pain may have on the individual is significant as demonstrated by Mphahlele, Mitchell and Kamerman (2012) and Wahab and Salami (2011) as it was often the reason for seeking consultation with a healthcare provider.

Table 1.1 Prevalence and intensity of pain in PLWHA in countries outside Africa

Authors	Sample	Location	Prevalence of Pain	Pain intensity
Merlin et al. 2013	1903 outpatients	Birmingham, United States of America	37%	23% had moderate pain
Miaskowski et al. 2011	270 community based sample	San Francisco, United States	91.8%	38.1% reported moderate pain 53.7% had severe pain
Aouizerat et al. 2010	321 outpatients	San Francisco, United States of America	55%	82% reported severe pain
Frich and Borgberg 2000	95 inpatients and outpatients	Denmark	74%	51% disturbing pain
Robbins, Chaiklang, and Supparatpinyo, 2013	254 outpatients	Thailand	22%	49.3% reported moderate to severe pain

1.1.3 **Effects of pain intensity on function and quality of life in PLHWA**

Pain has significant effects on function, quality of life and productivity. Studies assessing these factors in PLWHA are summarised in Table 1.3.

Function

An increase in pain severity has been linked to a decrease in functional activity as measured by Mann et al. (2015) who used the Euroqol 5D and brief pain inventory to assess physical function. Mann et al. (2015) restricted the population to those PLWHA who suffer from neuropathic symptoms and not necessarily chronic pain in general, therefore, the results

cannot be generalised. Pain was also independently associated with increased impairment in mobility, self-care and usual activities in a large American study in a population of PLWHA (Merlin et al. 2013). These studies suggest that the suffering experienced by PLWHA who have chronic pain affects all aspects of their daily lives and function. This is supported by several studies in Table 1.3 (Hughes et al. 2004; Astoro et al. 2007; Van As et al. 2009; Balderson et al. 2013; Merlin et al. 2013; Galantino et al. 2014).

It can be seen clearly from Table 1.3 that none of the studies used an objective physical outcome measure. Subjective measures such as the Short form health survey 36, Euroqol 5D, Brief Pain Inventory, Medical Outcomes Study- HIV Health Survey, World Health Outcomes International Classification of Function checklist, were used in the respective studies (Hughes et al. 2004; Astoro et al. 2007; Van As et al. 2009; Aragonés- López et al. 2012; Merlin et al. 2013; Balderson et al. 2013; Galantino et al. 2014; Mann et al. 2015). These are all subjective self-report measures with the exception of the World Health Organisation International Classification of Function checklist which utilises observation (Van As et al. 2009).

Van As et al. (2009) also used other standardised methods of measurement such as goniometry and the Oxford scale of measurement of muscle strength. While all of the above measures will give an indication of physical function, they are not as specific to actual performance of physical tasks when compared to the Simmonds battery (Simmonds et al. 1998; Simmonds MJ, 2002; Simmonds, Novy and Sandoval, 2005). This is a battery of physical tests that measure speed of movement, co-ordination, strength and endurance. The tests are measured through observation, timing of tasks and measurement of distances achieved by participants and have been used in the current study (Simmonds MJ, 2002). As demonstrated above, most studies in PLWHA with pain use a subjective measure of physical function to determine impairment, thus reporting on deficits in physical functioning may not correlate which the actual physical function of study participants. The review by Parker,Stein and Jelsma (2014) demonstrated that pain interference with function was of a moderate level which supports the findings of studies reviewed above (Parker, Stein and Jelsma, 2014).

Quality of Life

Quality of life, increased depression, anxiety and poor self-efficacy have been also been linked to chronic pain in HIV (Merlin et al. 2014). This quote taken from a qualitative study on patient perspectives of pain and HIV underlines how debilitating the problem of pain can be for an HIV infected individual to bear:

["Well, I've just got enough problems dealing with HIV, and trying to get myself clean, and then you throw in the pain on top of that, well, that's just something I don't need, right now. And it's just I mean; you can only take so many hard licks from one day, before you just gotta give up. And, if you got that damn pain sitting there, just gnawing, it's like somebody's gnawing on a bone, and you got that sitting there"] (Merlin et al 2014, p 4).

People living with HIV experience significant difficulty dealing with everyday life in terms of managing a chronic disease and several studies have reported on reduced quality of life in PLWHA (Hughes et al. 2004; Astoro et al 2007; Van As et al. 2009; Merlin et al. 2013). Factors in these populations associated with a decreased quality of life included mental functions, sensation and pain, digestive problems, neuromuscular function, mobility, usual activities , mood, age, opportunistic infection, ARV treatment for more than 3 months and CD4 count of less than 200cells/mL (Hughes et al. 2004; Astoro et al. 2007; Van As et al. 2009; Merlin et al. 2013) . Two studies, however, report a relatively high quality of life (Aragonés-López et al. 2012; Balderson et al. 2013). Aragonés-López (2012) cite the Cuban healthcare system outlined below as reasons for the higher level of quality of life in their cohort. Mandatory treatment in a sanitorium was a Cuban government policy in 1986 which has since changed to include optional treatment in a sanitorium. This now entails various national HIV programmes including training on how to live with HIV, socioeconomic and social support, close disease monitoring and good access to treatment (Granich et al. 1995; Gorry C, 2011). The reasons cited by the authors seem plausible given the comprehensive and structured healthcare programme available to those PLWHA in Cuba. The second study was carried out in a population who had been living with HIV/AIDS for a longer period of time (Balderson et al. 2013) which may account for the increased quality of life as these individuals most likely have learnt how to cope with living with HIV over time and developed significant support mechanisms in this time as well.

Table 1.2 Prevalence of pain, pain intensity and pain sites in Africa

Authors	Sample	Location	Prevalence of Pain	Pain intensity	Most common Pain Sites
Peltzer K 2013	735 treatment naive outpatients	Kwazulu Natal South Africa	Overall pain prevalence reported as common but no data available.	Not reported	Headache 32.1%,joint pain 23.6% ,22.9% reported chest pain, 15% reported muscle aches, 11.9% abdominal pain on initial assessment
Mphahlele, Mitchell and Kamerman, 2012	521 ambulatory out patients 396 attending an urban clinic, 125 attending a rural clinic.	South Africa.	**At the time of assessment** Rural -72% reported pain Urban - 56% reported pain **At the time of HIV diagnosis** Rural-76% reported pain Urban – 60% reported pain **Sought consult for pain resulting in HIV diagnosis** Rural – 73% Urban 92%	The median pain intensity was 5 (moderate intensity).	Most common pain sites identified were head, chest, and abdomen. In addition genital pain in rural sample and feet in urban sample.
Bhengu et al. 2011	149 outpatients	Kwazulu Natal South Africa	54 % reported pain. 19% who reported pain also reported numbness.	Not reported	32% reported headaches 22% reported types of pain
Narasimooloo, Naidoo and Gaede, 2011	100 inpatients	Kwazulu Natal South Africa.	91 % of the sample reported pain.	Mean- Worst pain 8.2 (severe) Mean – average pain 6.8 (moderate)	Not reported
Farrant el al. 2012	385 outpatients	South Africa	51% of the sample reported pain.	Not reported	Numbness or tingling in hands or feet 61%, no other sites reported
Harding et al. 2011	224 outpatients 192- South Africa 32- Uganda	South Africa, Uganda	82.6 % reported pain	Not reported	Not reported
K W Wahab and A K Salami, 2011	79 outpatients	Nigeria	27.8% 26.6% reported pain at the time of HIV diagnosis	Moderate 10% Severe 15%	44% lower limbs 38.1 % head, neck and abdomen

Table 1.3 Effects of pain on quality of life and function

Author	Location	Sample HIV-SN or a cross section of PLWHA ARV status	Quality of Life Outcome measure	Quality of Life	Functional Impairment Outcome measure	Functional Impairment
Van As et al. 2009	South Africa	45 ambulatory outpatients PLWHA 73.3% on ARV's 26.7% ARV naïve	None	Not reported	WHO ICF Checklist, dynamometry Oxford muscle testing and goniometry	Limitations in mobility, interpersonal relationships and general tasks and demands
Aragonés-López et al. 2012	Cuba	354 outpatients PLWHA 100% on ARVs	MOS-HIV health survey questionnaire	Higher scores for quality of life on the MOS-HIV health survey	MOS-HIV health survey questionnaire	Not reported on specifically.
Balderson et al. 2013	United states of America	452 outpatients PLWHA 100% on ARV's	SF 36	Health status decreased when pain severity increased	SF 36	Poor physical functioning when chronic illness was present.
Mann et al. 2015	United states of America	103 outpatients with HIV-SN ARV status not reported	EQ 5D	Not reported	EQ 5D BPI	Increased pain severity associated with increased activity impairment
Astoro et al. 2007	Indonesia	107outpatients PLWHA 31.8% on ARV's 68.2% ARV naïve	SF 36	Poor quality of life in 62.6% of the sample	SF 36	Physical function and mental function affected
Merlin et al. 2013	United states of America	1903 outpatients PLWHA ARV status not reported	EQ 5D	Not reported	EQ 5D	Impairment in mobility, self-care and usual activities
Hughes et al. 2003	South Africa	123 PLWHA – ARV naive 108 control group-community participants-HIV status unknown	EQ 5D	Health Related Quality of Life is severely compromised in PLWHA	EQ 5D	Health Related Quality of Life is severely compromised. Pain, mobility and usual activities are major problems

1.1.4 **Sites of Pain in People living with HIV/ AIDS**

As can be seen from Table 1.1 and 1.2, people with HIV associated pain experience pain at multiple sites including the extremities, gastrointestinal, head, neck, chest , muscles and joints. (Frich and Borgbjerg, 2000; Maritz et al. 2010; Bhengu et al. 2011; Miaskowski et al. 2011, Wahab and Salami, 2011; Farrant et al. 2012; Nasimango et al. 2012; Maree, Dreyer Wright and Makua, 2013). Whilst some studies haven't reported pain sites due to the lack of use of a specific pain outcome measure (Aouizerat et al. 2010; Narasimooloo, Naidoo and Gaede, 2011; Merlin et al. 2013), those that do, often choose the brief pain inventory to obtain this data. There seems to be no specific cause for the variation in pain sites, as these vary from chest pain to generalised body pain with no proven link to any specific medication, viral load or other variables (Frich and Borgbjerg, 2000; Bhengu et al. 2011; Mphahlele, Mitchell and Kamerman, 2012; Farrant et al. 2012; Nasimango et al. 2012; Maree, Dreyer Wright and Makua, 2013). This may be due to the complexity of chronic pain.

As mentioned previously, chronic pain is a complex phenomenon. There are several components that contribute to an individual's perception and experience of chronic pain. These include the biological aspect of the neurophysiology that occurs when one experiences pain, the psychological component of the emotions attached to the experience of pain and the social aspect where the environment and social interaction with others influence the individual's experience of chronic pain. Ultimately pain is an output from the brain based on the threat value perceived by the brain and the inputs vary significantly as shown by figure 1.2 below. As the pain becomes more chronic, central sensitization of the nervous system increases and this results the pain producing pain and other symptoms (motor, immune, endocrine) in an effort protect the body (Butler D S, 2000; Moseley GL, 2003; Moseley GL, 2007; Moseley and Flor 2012; Siddall and Cousins 2004). A detailed review of the mechanisms of chronic pain has not been included in this review as this is beyond the scope of this literature review.

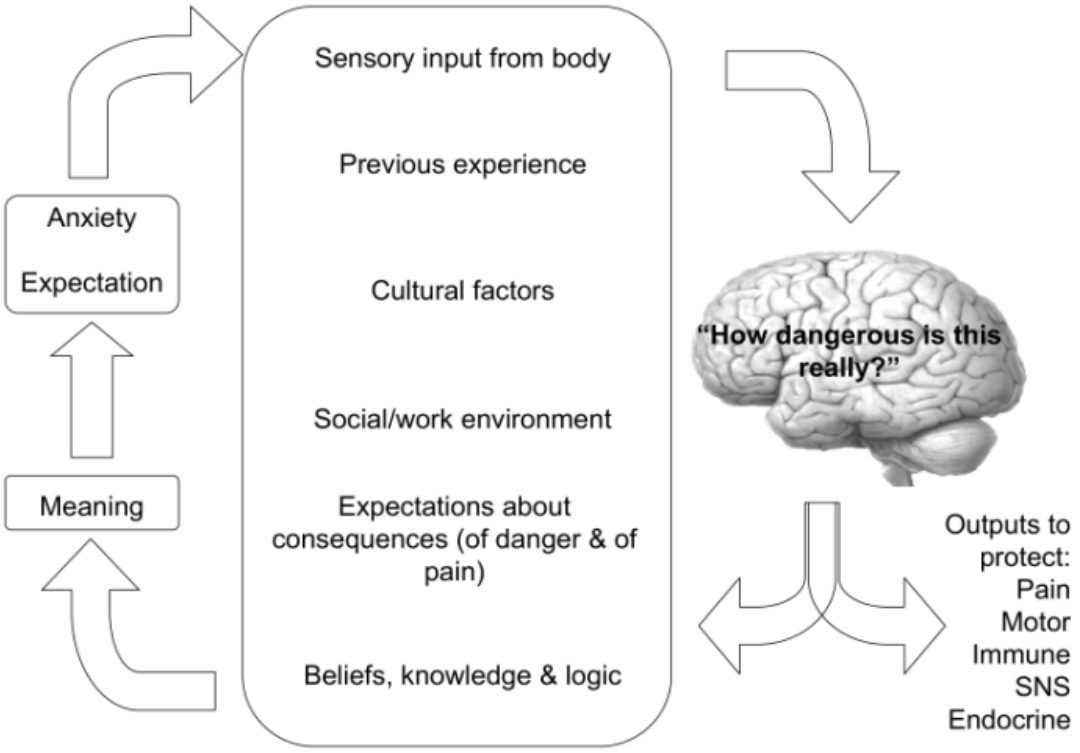

Figure 1.2 Inputs that affect pain perception taken from Moseley G L: Reconceptualising Pain According to Modern Pain Science. Physical Therapy Reviews. 2007; 12: 169–178.

In PLWHA aspects such as the stigma of HIV (Van Olmen et al. 2012; Cobbing, Hanass-Hancock and Deane, 2014; French et al. 2015; Parsons, Bond and Nixon, 2015; Denis P 2016) and the social isolation this brings contribute to the pain experience. Factors that complicate pain in PLWHA in Africa are poor access to healthcare and good healthcare facilities, cost of transportation to clinics and low socioeconomic status (Plazy et al. 2015; Camlin et al. 2016; Chetty and Hanass-Hancock 2016). The impact of psychosocial factors on pain in PLWHA can be illustrated by evidence that spiritual alternatives to medical management such as traditional healing (Camlin et al. 2016) impact on the treatment choices of the person living with HIV/AIDS. In addition, it has also been reported by PLWHA that when they complain of pain they are seen as lazy and their pain is not acknowledged as "real" (Maree, Dreyer Wright and Makua, 2013) which may have a psychosocial impact on the individual. Additionally there are various potential risk factors that have been linked to pain in PLWHA.

1.1.5 **Risk factors for pain in HIV/AIDS**

Potential risk factors have been identified by several studies(Schiffto et al. 2002; Hitchcock, Meyer and Gwyther, 2008; Koeppe et al. 2010; Maritz et al. 2010; Harding et al. 2011; Miaskowski et al. 2011; Wahab and Salami, 2011; Mphahlele, Mitchell and Kamerman, 2012). As pain is a complex cortical construct, the multiple risk factors are biopsychosocial and include age; sex; disease markers; education and other biopsychosocial variables.

Age

Increased age was identified by two studies in Table 1.4 as being a risk factor for the development of pain in PLWHA (Koeppe et al. 2010; Mphahlele, Mitchell and Kamerman, 2012;). Increased age has been shown to be a risk factor for chronic pain in a number of studies in other populations with chronic non cancer pain and musculoskeletal pain (Björnsdóttir, Jónsson and Valdimarsdóttir, 2013; Inoue et al. 2015; Croft and Mayhew, 2015; Nahin R L, 2015). The association of pain with increasing age may be related to co-morbidities such as the development of age related joint pain. However, this should be confirmed with further research in PLWHA using an age-stratified sampling design.

Sex

Female gender has been identified by several studies as a risk factor for the development of chronic pain in PLWHA (Koeppe et al. 2010; Miaskowski et al. 2011, Harding et al. 2011, Mphahlele, Mitchell and Kamerman, 2012). This finding is not restricted to PLWHA as females have been identified as being at higher risk to develop chronic pain (Munce and Stewart, 2007; Björnsdóttir, Jónsson and Valdimarsdóttir, 2013 Alhalabi, Alhaleeb and Madani, 2015; Deeny et al. 2015).The prevalence of chronic pain in females can be associated with psychosocial factors such as depression, coping strategies, catastrophising and stress (Munce and Stewart 2007, Bartley and Fillingim, 2013). Reviews on gender differences in pain confirm a higher prevalence of pain in women for a variety of reasons such as sex hormones, endogenous opioid mechanisms, genetic factors, pain coping , catastrophising, anxiety and gender roles (Bartley and Fillingim 2013, Melchior et al. 2016). One of the studies in Table 1.4 identified male gender as a potential risk factor (Hitchcock, Meyer and Gwyther, 2008). However, this finding does not correlate with research in the field of chronic pain currently. Possible reasons for this finding were not discussed by the authors. The female participants were much younger than the male participants in this study which may have been a confounding variable. The authors did not publish details of the male to female ratio or the age ranges present so it is difficult to draw any conclusions as to the reason why their results conflicts with the other studies.

Disease markers

A lower CD4 count or higher viral load was identified as a risk factor in two of the studies in Table 1.4 (Hitchcock, Meyer and Gwyther, 2008; Maritz et al. 2010) and a third study Schiffto et al. 2002 identified a history of AIDS diagnosis which can be linked to a lower CD4 count as a risk factor. Other studies have reported that the viral load does not play a significant role in the aetiology of the pain which does not give a clear picture of what predisposes an individual living with HIV/AIDS to develop chronic pain (Farrant et al. 2012; Mphahlele, Mitchell and Kamerman, 2012, Norval D A, 2004). However, one should take into account that a lower CD4 count can be related to other co-morbidities which may result in pain, as the individual has a poorer health status due to the higher viral load. A study by Singer et al. (1993) conducted over two years reported that pain was related to disease progression and reported an increase in new pains related to headaches and peripheral neuropathy. This study did not report on the level of pain intensity experienced by the participants, therefore, it is difficult to comment on the progression of pain in this study. The systematic review on pooled data of 6814 PLWHA showed mixed results with evidence linking disease markers to pain and other studies showing no link to the CD4 count (Parker, Stein and Jelsma, 2014). The use of disease markers as a risk factor for pain remains to be proven; therefore, one cannot make assumptions about the link with chronic pain in PLWHA. It is possible that disease markers may have no influence on pain.

Education

Studies in Table 1.4 report on the association of educational levels and chronic pain in PLWHA (Miaskowski et al. 2011; Mphahlele, Mitchell and Kamerman, 2012; Robbins, Chaiklang, and Supparatpinyo, 2013). A lower level of education seems to be related to the development of chronic pain; this may be attributed to a lower level of insight into the medical condition of HIV due to poor health literacy and may include a lack of knowledge about the disease. This may also be influenced by poor access to healthcare resources. Other studies have reported an association between lower levels of education and chronic pain in cohorts with back pain (Schmidt et al. 2007) and chronic pain (Zarei et al. 2012). Reasons cited are the lack of knowledge of disease and treatment; therefore, the participants do not attend to their health timeously and in an appropriate manner. This may be the case for PLWHA as well but has not been proven in research. More research is

needed using a longitudinal study design with larger sample sizes to determine if education is indeed a risk factor for pain in this population.

Other risk factors

The other risk factors that have been highlighted such as tobacco use, length of time since diagnosis (Koeppe et al. 2011), tuberculosis treatment (Hitchcock, Meyer and Gwyther, 2008) and length of time on ARV's (Robbins, Chaiklang, and Supparatpinyo, 2013) have not been verified by other studies and may be associated with HIV related pain. Most of the studies reviewed have been cross sectional in nature, and further research using longitudinal studies with large samples would be necessary to establish if this is indeed the case.

The study data by Koeppe et al. (2011) should be considered robust due to its longitudinal nature and the fact that it looked at a large sample size in a variety of settings. However, this study examined prolonged analgesic use as an indicator of pain experienced instead of a pain specific outcome measure such as the brief pain inventory. The finding that anti-depressant use is a risk factor for pain should be viewed cautiously as anti-depressants are often used to manage chronic pain in this population and the fact that these individuals were also prescribed analgesia is not surprising. Therefore, it cannot be assumed that the use of antidepressants and by implication the presence of depression is a valid risk factor for the development of pain.

The studies reviewed above show that various risk factors have been shown to be associated with pain in PLWHA such as age, female gender and lower educational levels. These have also been identified to be risk factors in populations with chronic pain. Disease markers remain an area of controversy as research reported does not demonstrate beyond doubt the association between pain in PLWHA and the disease marker. Therefore, disease markers and other risk factors identified above will require further research with longitudinal studies that look at these specific risk factors.

Table 1.4 Risk factors for HIV related pain

Authors	Sample	Location	Risk factors identified
Hitchcock et al. 2008	354 outpatients Public hospital clinic	Pretoria, South Africa	Higher incidence of neuropathic pain in males Lower CD4 counts Treatment for tuberculosis
Koeppe et al. 2011	931 outpatients Private, public and university based clinics	United States of America	Lower CD4 counts History of opportunistic infections Length of time since HIV diagnosis (4years or more) Increased age Tobacco use Higher incidence of pain in females Use of anti-depressants or anxiolytics Public or no health insurance
Mpahlehle et al. 2012	521 ambulatory outpatients Urban and rural clinics	South Africa	Decreased pain linked to ARV's –rural cohort Age –urban cohort
Miaskowski et al. 2011	270 community based sample	San Francisco, United States	CD4 count not associated with pain severity Lower level of education Female gender
Harding et al. 2011	224 outpatients,192- South Africa 32- Uganda	South Africa, Uganda	Female gender
Wahab and Salami, 2011	79 outpatients	Nigeria	Not related to stage of HIV infection
Robbins, Chaiklang, and Supparatpinyo, 2013	254 outpatients	Thailand	Time on ARV treatment Lower education level Positive depression screening

Table 1.5 Under treatment of pain in HIV

Authors	Location	Sample (only those participants reporting pain)	Pain locations	Appropriate Treatment	Outcome measure	Conclusion
Mphahlele et al. 2012	South Africa	198 ambulatory outpatients reported pain out of 512 participants	Headaches, chest pain, abdominal pain and feet pain	No analgesia-Rural 29% Urban 43% Appropriate strength analgesic medication Rural 0% Urban 8%	Standardised interview	Significant under treatment for both cohorts. Prescribed inappropriate or no medication to treat pain
Narasimooloo, Naidoo and Gaede, 2011	South Africa	91 inpatients	Not reported	30%-No analgesia for pain relief	Pain management index and medical chart review	Significant under treatment of pain.
Farrant el al 2012	South Africa	197 outpatients	Not reported	Poor pain/symptom management measured according to the burden of symptoms reported	None reported.	Pain found to be inadequately treated
Maree, Dreyer Wright and Makua 2013	South Africa	436 outpatients	Headaches, chest pain, mouth, limb pain and foot pain	40% of sample still experienced pain despite taking medication prescribed 60% reported that the amount of medication given was insufficient to last till the next clinic visit	Structured interview	Staff at the clinic lacked knowledge of pain and appropriate pain management
Frich and Borgberg 2000	Denmark	84 inpatients and outpatients	Headaches, gastrointestinal tract and extremities	77% of patients reported that treatment of pain was inadequate at baseline interview.	Pain management index and medical chart review	Inadequate treatment of pain that improved over time of the study.
Robbins, Chaiklang, and Supparatpinyo, 2013	Thailand	69 outpatients	Not reported	86% reported inadequate pain management according to scores of less than zero on the pain management index.	Pain management index	Inadequate treatment and the WHO guidelines were not followed.

1.2 Management of chronic pain in people living with HIV/AIDS

In this section I will be reviewing the pharmacological and non-pharmacological approaches to chronic pain management in HIV. The literature on the under treatment of pain is summarised in Table 1.5. Several studies reviewed have looked specifically at neuropathic pain as this is prevalent in PLWHA.

Some of the studies reviewed in Table 1.5 have pointed to the fact that pain reported by participants was undertreated. However, the lack of specific standardised outcome measures or lack of detail in methodology reporting how this data were collected, reduces the robustness of these results (Narasimooloo, Naidoo and Gaede, 2011; Farrant et al. 2012; Mphahlele, Mitchell and Kamerman, 2012). Despite the lack of standardised outcome measures, several papers have reported under treatment of HIV related pain in Africa and in other countries (Frich and Borgbjerg, 2000; Narasimooloo, Naidoo and Gaede, 2011; Farrant et al. 2012; Mphahlele Mitchell and Kamerman, 2012; Robbins, Chaiklang, and Supparatpinyo, 2013; Maree, Dreyer Wright and Makua, 2013).

Mphahlehle (2012) and colleagues reported that no analgesia was given to 29% of the rural cohort and 43% of the urban cohort suffering from pain in their study. This study also reported that the appropriate strength analgesic medication was not reported by any rural participants and only 8% of urban participants reported that the analgesia provided was of appropriate strength (Mphahlele, Mitchell and Kamerman, 2012). Similarly, in a study of inpatients with HIV/AIDS 30% of participants suffering from pain received no analgesia (Narasimooloo, Naidoo and Gaede, 2011). Further, Maree, Dreyer Wright and Makua, (2013) reported that 40% of the cohort still experienced pain despite taking prescribed medication while 60% reported that the amount of medication given was insufficient to last till the next clinic visit. The similarity of findings in the studies reviewed above reveal that there may be a need to improve the medical management of pain experienced by PLWHA in South Africa.

1.2.1 Pharmacological Management

Due to the nature of HIV related pain having multiple aetiologies, prescribing the correct pharmacological intervention may be difficult as the aetiology is not always known. In South Africa the majority of treatment available to PLWHA who experience significant pain is currently restricted to pharmacological interventions. This is in keeping with the global view examined in reviews on management of HIV related pain (Phillips et al. 2010; Kamerman

and Mitchell, 2011; Parker,Stein and Jelsma, 2014; Finnerup et al. 2015). In addition, the pharmacological management of HIV related pain appears to prioritise the treatment of neuropathic pain.

The review by Kamerman and Mitchell (2011) advises the use of published guidelines to manage neuropathic pain in HIV. In the absence of population appropriate evidence based guidelines for the management of neuropathic pain, the reviewers recommend the World Health Organisation (WHO) analgesic step ladder approach to chronic pain (Kamerman and Mitchell, 2011). This recommendation is supported by the other reviews which recommend specific analgesic medication according to clinical trials and research reviewed (Finnerup et al. 2015).

Finnerup et al. (2015) recommended tricyclic antidepressants, serotonin noradrenalin reuptake inhibitors, pregabalin and gabapentin as first line treatment for neuropathic pain. Tramadol, lidocaine and capsaicin patches were weakly recommended as second line treatment and a weak recommendation for strong opioids and botulinum toxin A was made. Finnerup et al. (2015) concluded that HIV neuropathic pain was found to be more difficult to treat than other types of pain from the research examined. The authors also outlined that large placebo responses, modest drug efficacy and the variability in diagnostic criteria for neuropathic pain contribute to the weakness of recommendations for treatment of neuropathic pain.

The South African guidelines for neuropathic pain also advise the first line use of gabapentin or pregabalin, amitriptyline or other tricyclic antidepressants and serotonin noradrenalin reuptake inhibitors such as duloxetine and venlafaxine (Chetty et al. 2012). Thereafter a combination of these drugs is recommended as second line treatment, and tramadol followed by strong opioids is recommended as a third line of treatment. The South African guidelines for neuropathic pain also highlighted the lack of South African data for pharmacological management of painful HIV neuropathy (Chetty et al. 2012). The national development plan presented by the South African Department of Health in 2015 includes the goal of ensuring all PLWHA have adequate access to treatment and ARV therapy but there is no specific mention of the treatment of pain experienced by PLWHA (Department of Health 2014).

Opioids

According to Koeppe et al (2010), the use of medication and specifically opioids is not effective in the management of pain in individuals with HIV (Koeppe et al. 2010). However, the use of opioids in HIV related pain is controversial with research undecided on whether

the use of opioid drugs is efficacious. This is demonstrated by a Cochrane review which concluded that the analgesic effect of opioids in neuropathic pain is questionable with enough research proving that it works and just as much research showing that it is not that effective McNicol, Midbari and Eisenberg (2013). A review funded by the neuropathic pain special interest group of the International Association for the Study of Pain looked at studies and clinical trials that were published and unpublished as well as the possible bias in the reporting of study outcomes. This review recommended opioids only as a third line medication in the management of neuropathic pain (Finnerup et al. 2015).

Clinical guidelines by the American Pain Society and the American Academy of Pain Medicine recommend the use of opioids in chronic non cancer pain of moderate to severe intensity that is affecting quality of life and daily function. This recommendation is accompanied with a caution that the potential benefits of opioid prescription should outweigh the potential harmful effects of possible addiction or overuse (Chou et al. 2009). Chronic pain in HIV falls into the category of non-cancer chronic pain; however, these guidelines do not specifically address HIV related pain.

Therefore, the research does not seem to support the use of opioid medication for HIV related pain. The guidelines reviewed, however, concentrate mostly on neuropathic pain in PLWHA and ignore other types of pain experienced by PLWHA. Neuropathic pain in PLWHA has been identified by researchers as a common symptom. This could be related to the fact that historically, ARV's used early on in the HIV epidemic produced the side effect of neuropathic pain. More studies are required that look at the use of opioids in the management of chronic pain in PLWHA to establish if this is a viable management option.

Amitriptyline

Amitriptyline is a tricyclic antidepressant that has been used to treat chronic neuropathic pain with some efficacy (Finnerup et al. 2015; Moore et al. 2015). A comparative study that looked at the efficacy of amitriptyline when compared to pregabalin in chronic low backache (Kalita et al. 2014) found that amitriptyline performed better in the reduction of pain and disability. However, the results of this study are questionable due to the small sample size and lack of a placebo arm (Kalita et al. 2014). Dinat et al. (2015) looked at the use of amitriptyline in neuropathic pain in HIV as it is the first drug of choice for the treatment of diabetic neuropathy and post herpetic neuralgia, according to the WHO guidelines (World Health Organisation, 2016) (World health organisation 2016). The results showed that amitriptyline is no better than placebo at treating neuropathic pain in HIV (Dinat et al. 2015). An updated Cochrane review supported these findings by reporting that there is only low

quality evidence available that amitriptyline is significantly better than placebo in treating neuropathic pain. The authors concluded that there is a possible overestimation of treatment effects in previous research done (Moore et al. 2015).

A Maltese study looked at the management of chronic orofacial pain with the prophylactic use of low dose amitriptyline. The study reported good results with resolution of pain in 45.5% of the mid facial pain participants and 23% in migraine sufferers. The participants were followed up for 3 years which strengthens the veracity of these results. Some of the participants, however, were treated with amitriptyline and other tryptans as well as non-steroidal anti-inflammatories. The results can therefore not be fully attributed to the use of low dose amitryptiline and further research in this population may be warranted to establish the drug efficacy reported by this study (Agius, Jones and Muscat, 2014).

Amitryptiline is used in the management of chronic pain in other conditions such as low back pain and orofacial pain with efficacy (Kalita et al. 2014; Agius, Jones and Muscat, 2014), thus it may have benefit in treating chronic pain in PLWHA. The study on neuropathic pain does not demonstrate efficacy in PLWHA but perhaps more studies are necessary in this population to establish drug efficacy (Dinat et al. 2015). Amitryptiline may be a useful modality to manage other types of pain in PLWHA, however, research needs to focus on HIV related pain not only neuropathic pain in PLWHA.

Anticonvulsants

Anticonvulsants have been recommended as a treatment option in neuropathic pain (Chetty et al. 2012; Finnerup et al 2015) with literature of varying strengths supporting these recommendations.

The study by Kalita et al. (2014) demonstrated that the anticonvulsant pregabalin did not yield better results in reducing pain and function in individuals with chronic back pain than amitryptiline. This serves to emphasize that pregabalin may be beneficial for neuropathic pain but is perhaps not the drug of choice for all types of chronic pain. A study that examined the use of anticonvulsants in neuropathic pain, however, showed that gabapentin and nortriptyline in combination reduced pain and improved sleep significantly which led to a slight improvement in quality of life. These drugs in combination had better efficacy than when used alone in this trial (Gilron et al. 2009). A Cochrane review in 2013 looked at the use of anti-epileptic medication in neuropathic pain and fibromyalgia (Wiffen et al. 2013). This review supported the use of pregabalin and gabapentin in neuropathic pain in diabetic neuropathy and post herpetic neuralgia with second tier level evidence. It also

recommended the use of pregabalin in fibromyalgia and central neuropathic pain (Wiffen et al. 2013).

The review reported a lack of second tier evidence for the use of anti-epileptic medication in HIV peripheral neuropathy. It was interesting to note that none of the other anticonvulsant drugs were found to be useful in management of neuropathic pain (Wiffen et al. 2013). So evidence does seem to indicate that anticonvulsants have a place in the management of pain, more specifically neuropathic pain, which may be relevant to the population of PLWHA who suffer from painful peripheral neuropathy although evidence for efficacy in this population seems to be limited. Once again more research is necessary in HIV related pain that does not focus on neuropathic pain alone.

Cannabis

The use of cannabinoids in the management of chronic pain has been controversial, mostly due to the fact that it is an illegal narcotic in most countries and the side effects of cognitive and motor dysfunction that occur when used for a prolonged period of time (Finnerup et al. 2015). However, there is evidence in favour of the use of cannabinoids or cannabis in chronic pain management, especially for pain that does not respond to other medication (Boychuk et al. 2015). An Australian study looked at a cohort of community based participants suffering from non-cancer pain and found that 16% had used it for pain relief and a further 24% would use it for pain relief if they were able to access the drug (Degenhardt et al. 2015). The average amount of pain relief from cannabis use reported by these participants was 70% while pain relief from usual medication was only 50%. However, these results are compounded by a high prevalence for recreational cannabis use in this study with 43% of participants reporting that they had used the drug previously for recreational purposes (Degenhardt et al. 2015). There were also significant concomitant factors present which could have been confounding variables such as the presence of mental illness, substance abuse, higher pain interference and higher use of opioids over a longer period of time (Degenhardt et al. 2015).

The use of smoked cannabis in painful HIV sensory neuropathy has been tested and found to be beneficial with a 34% reduction in pain when compared to placebo. The authors do note, however, that the relaxing effects, reaching a “high” or “unblinding” could have attributed to the reduction in pain (Abrams et al. 2007). The intervention took place over five days with no follow up period, which also questions the long term efficacy of the cannabis for neuropathic pain. These results were supported by another short term study (follow up

period of two weeks post intervention) where the participants reported 30% pain relief when compared to placebo (Ellis et al. 2009).

As demonstrated above, efficacy of pharmacological interventions in the field of chronic pain is inconclusive. In the field of HIV related pain most studies have been restricted to neuropathic pain. This is only one type of pain experienced by PLWHA and there is a need for further research in this population. Research done shows that there generally isn't good efficacy for neuropathic pain because placebo has been shown to work as well as pharmacological agents(Moore et al. 2015; Dinat et al. 2015) However, some agents such as cannabis have shown positive results (Ellis et al. 2009; Degenhardt et al. 2015) for chronic and neuropathic pain. Generally, the evidence is weak (Finnerup et al. 2015) but recommendations have been made for first line treatment of neuropathic pain with tricyclic antidepressants, serotonin noradrenalin reuptake inhibitors, pregabalin and gabapentin with moderate levels of evidence. There is thus a clear need for further research and alternative pharmacological options for the management of chronic pain in HIV as studies have focused on neuropathic pain in this population while ignoring other types of HIV related pain.

1.2.2 **Biopsychosocial approach to chronic pain**

Chronic pain is multi-factorial in any situation and this is further complicated in PLWHA by aspects such as the stigma of HIV as mentioned previously (Van Olmen et al. 2012; Parsons, Bond and Nixon, 2015; French et al. 2015; Denis P 2016). As outlined previously, the socioeconomic factors and access to healthcare in South Africa add to the complexity of the chronic pain experience of PLWHA in this country (Cobbing, Hanass-Hancock and Deane, 2014; Plazy et al. 2015, Camlin et al. 2016, Chetty and Hanass Hancock, 2016). Alternatives to traditional medical management such as traditional healing (Camlin et al. 2016), often play a role in the South African context. Others perception of pain can also play a role as reported by Maree, Dreyer Wright and Makua (2013) where complaints of pain were not perceived as real.

A biopsychosocial approach to other forms of chronic pain has long been advocated as an effective pain management approach (Siddall and Cousins 2004; Cheatle M D 2016).This involves a holistic view of the individual using a three way approach to manage chronic pain. This includes a biological approach to manage the physiological aspects of chronic pain such as pain intensity, a psychological approach to manage the emotional aspects of pain such as catastrophising and depression and a social approach which looks at the individuals

social environment and interaction which provides the context in which the chronic pain is occurring (Siddall and Cousins 2004; Cheatle M D 2016).

A review of management for chronic pain in HIV proposed that the biopsychosocial approach is the best option (Marcus et al 2000). Whilst this might be the case in HIV management in other countries/continents, it is far from being the case in Africa/South Africa where medical management is mostly used. This is illustrated by the studies in Table 1.5 describing management of HIV related pain (Narasimooloo, Naidoo and Gaede 2011; Farrant et al. 2012; Mphahlele, Mitchell and Kamerman, 2012; Maree, Dreyer Wright and Makua, 2013; Chetty and Hanass Hancock, 2016).

The management options for managing pain in this population should include interventions for the biological, psychological and social aspects of pain. This would then ideally include both pharmacological and non-pharmacological approaches, the latter including self-management and interdisciplinary programmes.

1.2.3 **Non-Pharmacological Management**

Non-pharmacological interventions have been largely neglected in PLWHA globally and in South Africa (Kamerman and Mitchell, 2011; Parker,Stein and Jelsma, 2014). The standard practice currently is management through medication (Kamerman and Mitchell, 2011; Parker,Stein and Jelsma, 2014). Evidence pertaining to the use of non-pharmacological treatment in the management of chronic pain in PLWHA is sparse. However, more researchers are starting to look at non-pharmacological interventions as pharmacological interventions have been shown to have inconsistent rates of efficacy in the management of pain as shown above in the section on pharmacological management (Koeppe et al. 2010; Moore et al. 2015; Dinat et al. 2015). A few non-pharmacological approaches will be reviewed below but it is important to note that there are many non- pharmacological approaches available for the management of chronic pain and it is beyond the scope of this literature review to examine all of them.

Cognitive behavioural therapy and group therapy

Cognitive behavioural therapy (CBT) has been used as a treatment modality in individuals with chronic pain in the past (Thorn and Kuhajda, 2006; Haraldseid, Dysvik and Furnes, 2014; Furnes, Natvig and Dysvik, 2014) and remains a treatment modality of choice in many multidisciplinary pain clinics. Studies have reported benefits including reduced pain intensity, pain interference, improved mental health, socialisation, pain related functioning, acceptance of pain and lifestyle changes (Thorn and Kuhajda, 2006; Cucciare, Sorrell and Trafton, 2009;

Huggins et al. 2012; Trafton et al. 2012; Haraldseid, Dysvik and Furnes, 2014) . In South Africa, the South African Neuropathic Pain guidelines (Chetty et al. 2012) recommend CBT as a non-pharmacological intervention for neuropathic pain based on a review of evidence that showed modest efficacy for chronic pain (Turk et al. 2010).

The efficacy of cognitive behavioural therapy in a population of PLWHA suffering from HIV related pain has shown a reduced pain intensity of two points on a numeric rating scale (NRS), a clinically significant improvement in pain according to the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) recommendations (Dworkin et al. 2008). Reduced pain anxiety, pain interference in overall functioning and improvement in mental health symptoms such as mood, and an improvement in pain acceptance have also been demonstrated (Huggins et al. 2012; Trafton et al 2012). The cohort and intervention was the same for three studies (Huggins et al. 2012; Cucciare, Sorrell and Trafton, 2009; Trafton et al. 2012), with the researchers using different questionnaires focussing on different outcomes. The intervention was carried out on outpatients at 3 primary care clinics in San Francisco. The fact that three studies were carried out in the same cohort using the same intevention may indicate that CBT has not been widely used with PLWHA who suffer from chronic pain. The sample size was small 60 for the studies by Trafton (2012) and Cucciare (2009) and 45 for the Huggins (2012) study which restricts the reported results to this cohort alone. The attendance at the CBT group was also poor with only 35% attending the total CBT sessions (Huggins et al. 2012; Trafton et al. 2012). Therefore, significant changes reported may not have occurred due to the CBT intervention alone, although participants in one of the studies rated their satisfaction with CBT very highly (Trafton et al 2012). The high participant satisfaction may indicate that even a small number of CBT sessions are beneficial. However, in this context there was no control group present, therefore, findings may not be as valid as confounding variables and other factors may have played a role in the outcomes reported.

Satisfaction with CBT as an intervention is portrayed well in the words of this study participant who said [‘‘Most of the group participants dug deep and shared, there were a lot of tough stories, and then you see you are not the only one to struggle.’’] (Haraldseid, Dysvik and Furnes, 2014, p 16). This statement suggests benefits of group interactions. Social support, a warm group climate, a sense of fellowship and trust which consequently leads to a deeper level of sharing and an improvement in the daily lives of participants are of value in the intervention (Haraldseid, Dysvik and Furnes, 2014). Studies have shown that benefits of group interaction, support, trust and a sense of fellowship are important aspects of participating in a therapeutic group (Mundell et al. 2012; Furnes, Natvig and Dysvik, 2014).

This is highlighted by this quote taken from the study by Mundell et al. (2012) ["I made friends and seeing those women I realized that I was not the only one, it gave me courage and confidence to live my life."] Improved mental health, lifestyle changes, improved socialisation were some of the benefits reported (Mundell et al. 2012, p 6).

It is still debatable whether cognitive behavioural therapy is the answer to pain management in PLWHA. The benefits of cognitive behavioural therapy have not been found to last longer than 6 months in this population. Studies with longer follow up periods are required to establish the long term benefits of CBT (Evans and Fishman, 1997; Molassiotis et al. 2002; Huggins et al. 2012; Trafton et al. 2012). In a case study by Thorn and Kuhajda, (2006), it is reported that CBT groups can run for up to 3 years with the same participants, however, there is a lack of research to prove that this is current accepted practice for CBT and chronic pain. This would appear to be a resource intensive approach to treatment which may not be appropriate in a South African setting.

A study comparing CBT to peer support counseling (PSC) found the benefits of peer support counseling lasted longer than CBT (Molassiotis et al. 2002). The changes noted at 3 months in the CBT group were not present at 6 months post intervention while the PSC group had significant changes noted in quality of life and psychological variables. This suggests that CBT may need to be an ongoing therapy rather than a once off programme although the effectiveness of this approach needs further research. The cost implications may restrict the use of ongoing CBT. These study results (Molassiotis et al. 2002) may also suggest that a group which is facilitated by a peer may be more successful than one run by a healthcare professional and may be worth exploring in further research. These results are supported by Lorig, Ritter and González (2003) who reported that the use of peer leaders are beneficial when using a self-management programme due to the modelling of behaviour that occurs, the increased availability of peer leaders versus healthcare professionals and the fact that peer leaders speak the language of participants (Lorig, Ritter and González,2003).

Evans et al. (2003) compared CBT and individual psychotherapy in a group of PLWHA who suffered from painful peripheral neuropathy. She reported a significant reduction in pain intensity and pain interference of at least two points on the numeric rating scales. However, the high attrition rate from this study of 45.9% lead to the researcher concluding that psychological interventions such as CBT and psychotherapy may not be viable or feasible in this population**.** This casts some doubt on whether CBT or other psychological interventions are effective interventions that can produce long term results in PLWHA, particularly in resource poor settings.

Mindfulness based Practice

Mindfulness based practices have long been advocated in the field of chronic pain management. Some examples of the mindfulness based practice approaches such as meditation, hypnosis and relaxation therapy are reviewed below.

Hypnosis

Hypnosis has been assessed as a treatment modality in several populations suffering from pain such as chronic low back pain (Tan et al. 2015), work related musculoskeletal disorders (Roja et al. 2013), dysmenorrhea (Shah et al. 2014), burn patients (Patterson et al. 1992) and multiple sclerosis (Jensen et al. 2016). Results vary with some reports of significant reductions in pain intensity ratings (Roja et al. 2013; Tan et al. 2015; Jensen et al. 2016) and no significant differences when compared to other interventions (Shah et al. 2014). This may be due to the heterogeneity of diagnoses and types of pain in the study cohorts as well as the type of hypnotic intervention delivered which ranged from self-hypnosis to cognitive hypnotherapy (Roja et al. 2013; Shah et al. 2014; Tan et al. 2015; Jensen et al. 2016).

Hypnosis has also been used to manage pain in PLWHA demonstrating a significant reduction in pain (4 points on the total McGill pain questionnaire score) and an improvement in quality of life and depressive symptoms 3 weeks post intervention (Dorfman et al. 2013). Unfortunately, the reduction in pain was only reported to have lasted 7 weeks post intervention when the last follow up assessment was done. The study design made it difficult to reliably ascertain that these changes were due to the hypnosis (Dorfman D 2013). A randomised controlled trial is necessary to determine if hypnosis can be used to effectively manage pain in this population, however, due to the very nature of hypnosis this is difficult to achieve as is the case with most rehabilitation modalities.

Meditation

Meditation is another therapeutic modality used in chronic pain with some positive results reported, including the reduction of anxiety and depression, increased pain acceptance and feelings of control over pain (La Cour and Petersen, 2014), reduction of pain perception (Bakhshani et al. 2016) and reduction of stress, symptom severity and sleep disturbance (Cash et al. 2015). These studies were stronger than the hypnosis studies as they all included a control group but had small sample sizes which may have affected the significance of the reported results. Efficacy of meditation or mindfulness has been demonstrated in cohorts of PLWHA (Nicholas et al. 2007; Duncan et al. 2012). Nicholas et al. (2007) reported that meditation was scored second highest for efficacy from all the complementary medicine strategies for self-management of peripheral neuropathy

symptoms in PLWHA, while Duncan et al. (2012) demonstrated that mindfulness meditation reduced the frequency of symptoms at 3 and 6 month follow up and reduced the associated stress experienced at 3 months. Therefore, meditation may have some possible benefit in management of pain in PLWHA; however, this requires further research using randomised controlled trials which compare different interventions.

Relaxation Therapy

Relaxation therapy has been advocated in the treatment of chronic pain for chronic headache and fibromyalgia sufferers. There are several types of relaxation therapy including guided imagery, muscle relaxation and autogenic training which can also include diaphragmatic breathing.

A systematic review on the use of relaxation therapy in fibromyalgia and chronic fatigue syndrome concluded that there was a moderate effect on acute pain when guided imagery was used. There is no agreement on the content of visualisation that should be used in the techniques and no indication of the benefit of the technique in chronic pain. The studies reviewed had conflicting results on the long term benefits. The review included data on 650 fibromyalgia sufferers and 88 chronic fatigue sufferers with a range of relaxation therapy techniques using randomised controlled trials. Blinding was not possible and the review reported that it was difficult to ascertain the effects of relaxation therapy as many studies included it as a component of a multimodal therapy programme, thus the authors only included those trials which used the relaxation therapy on its own (Meeus et al. 2015). The duration of relaxation therapy varied from one session to four weeks. Techniques and protocols varied as well which is possibly the reason that results conflict. The risk of bias in these studies is high as the therapist cannot be blinded from the study participants due to the nature of the technique.

A second review on guided imagery in an arthritis and rheumatic disease population demonstrated that guided imagery is beneficial in decreasing pain, anxiety and fibromyalgia symptoms, improving self-efficacy, mobility and psychological well-being. The review covered a sample of 287 participants and was restricted to the guided imagery technique alone. The study concluded that there was an unclear risk of bias due to lack of blinding and the use of self-report measures alone to measure study outcomes. The duration of the techniques also varied and longer follow up would be necessary to establish permanence of the results reported (Giacobbi et al. 2015).

A study done on chronic tension type headache patients compared the effects of relaxation therapy, acupuncture and physical training in a cohort of 90 headache sufferers and 88

matched healthy participants. Their results indicated that physical training was significantly better in reducing symptoms than acupuncture (p=0.036) after three months. At 6 months there was no significant difference in the symptom profile between the three intervention groups indicating that any changes that may have occurred at three months were not permanent. Relaxation therapy was found to significantly improve sleep and vitality when compared to acupuncture (p=0.04) at the six month follow up assessment. However, this was restricted to a particular component of the symptom profile and did not have an overall effect when the total symptom profile was calculated (Soderberg et al. 2011). The intervention period ranged from two to three months and 10 -12 sessions for each technique. This variability in the length of intervention may have been a confounding variable, however, the techniques were fairly standardised and delivered by the same group of experienced therapists which adds to the reliability of the results. The study did not use a pain specific outcome measure, therefore, the impact of the relaxation therapy technique on pain cannot be commented on. The risk of study bias is high due to the lack of blinding as mentioned previously. Despite this there seems to be merit in this technique that would require further research.

Relaxation therapy has been used in the HIV population but mainly for stress management and the examination of any possible effect on immune status. A study using relaxation therapy as part of a cognitive behavioural intervention reported better emotional coping and quality of life but these were modest findings which the authors admit are not definitive (McCain et al. 2008). An improved immune status was reported in the results but could not be linked to any change in stress levels. The study participants were not highly stressed pre-intervention so it was difficult to establish whether the effects were linked to stress reduction. Another study on 150 HIV positive women also looked at the effect of relaxation therapy as part of a cognitive behavioural stress management programme. The authors reported a significant reduction in cortisol post guided imagery, however, confounding variables such as duration of relaxation therapy, lack of data about practice outside the study, varying times of collection of the saliva for analysis and the limited follow up (only during study period of ten weeks) cast doubt on the integrity of these results (Jones et al. 2014).

The reviewed research has mixed results which is possibly due to the lack of a standardised protocol for these techniques and the variety of relaxation therapeutic techniques used (McCain et al. 2008; Jones et al. 2014; Meeus et al. 2015; Soderberg et al., 2011; Giacobbi et al. 2015). It is also difficult to achieve blinding in these studies due to the nature of the technique which requires interaction with the health care practitioner thus the risk of study bias is high. There are indications that relaxation therapy has benefits but its role in the

management of chronic pain requires further research using randomised controlled trials with standardised interventions and longer follow up periods to establish permanence of any effects observed. There is also a lack of research with this modality in PLHWA who experience chronic pain. The above research demonstrates that this may be a useful modality in pain management for this population.

Acupuncture and Massage therapy

Acupuncture and massage therapy have been studied widely in a number of chronic pain populations (Scharf et al. 2006; Suarez-Almazor ME, 2010; Field et al. 2015; Damapong et al. 2015; Wamontree et al. 2015, Ji et al. 2015, MacPherson et al. 2015; Shin et al. 2015). For massage therapy, the results indicate reductions in pain intensity and tissue hardness (measured with a tissue hardness meter which gives a reading of percentage of tissue hardness) and an increased range of motion (Damapong et al. 2015). However, many of these studies reported results after short term follow up periods of one to four weeks only with the exception of three studies that had follow period of 12 weeks(Suarez-Almazor et al. 2010), 26 weeks (Scharf et al. 2006) and 12 months (MacPherson et al. 2015) respectively. The longevity of the shorter study results cannot be commented on (Field et al. 2015; Damapong et al. 2015; Wamontree et al. 2015). The heterogeneity of the different treatment techniques used in these studies also do not allow for adequate comparison of all the data collected in these studies. Acupuncture has also been researched in several chronic pain populations with conflicting results of improvement of pain or no significant differences in outcomes used in the studies (Scharf et al. 2006; Suarez-Almazor et al. 2010; MacPherson et al. 2015; Shin et al. 2015; Ji et al. 2015).

Acupuncture and massage therapy were compared to the usual biomedical approach in a study that used focus groups and interviews to establish participants' views on treatment benefits (Ho and Robles, 2011) in a cohort of PLWHA who were experiencing peripheral neuropathy. It was surprising to note in this study that even though the study participants reported temporary pain relief from the complementary modalities received, they believed that these modalities were a good long term option for pain relief, even to the extent of discontinuing their ARV medication for periods of time as they felt the complementary options were more beneficial (Ho and Robles, 2011). This is a concerning finding as the discontinuation of ARV's would lead to the development of ARV resistance over time and a possibility of disease progression depending on the amount of time the ARV was discontinued.

Another study in a group of 46 individuals living with HIV in the United States of America compared massage, acupuncture and a combination of massage and acupuncture to a

control group who did not access these treatments. The subjective experiences of the participants revealed that acupuncture and massage whether used individually or combined, reduced pain, improved energy levels, decreased anxiety and improved sleep. The control group did not exhibit these changes (Henrickson M, 2001).This study did not use standardised outcome measures. Outcome measures included a numeric rating scale to rate the impact of treatment, a 19 item questionnaire used to rate the perception of treatment impact and CD4 counts that were measured at baseline and post treatment. The lack of standardised outcome measures such as the BPI or Becks Depression Inventory makes the results questionable as only subjective reports of symptom relief via telephonic interview were used to gather this data and no significant changes were noted in the CD4 counts taken (Henrickson M, 2001).

A Canadian mixed methods study in 194 PLWHA revealed that massage was one of the most common choices among participants (Mulkins et al. 2014). At the 18 month follow up visit 81% reported the use of a massage therapist and 15% reported the use of an acupuncturist. The results showed an improvement in pain, energy, stress and overall well-being, however, these were not attributed to a specific modality and therefore one cannot draw the conclusion that massage therapy was responsible for the changes in health status noted. It is important to note the possible impact of the “care effect” that these type of interventions produce where the individual feels that the manner in which they are treated is much warmer and that the service provider cares about how they feel. This is demonstrated by the following quote taken from this study: [“I spend most of my days alone but I know I can come here and find someone who is going to listen to my issues and try their best to help me. That means so much to me..... Susi (Reiki practitioner) knows where I am coming from. She has been treating me for a while now and I know she is healing me. She literally lifts weight off my shoulders”] (Mulkins et al. 2014,p 220).

The studies cited above reveal that CAM and specifically hypnosis, meditation, relaxation therapy, acupuncture and massage therapy are being used by PLWHA for various health benefits such as the management of fatigue, stress, neuropathy and other symptoms (Henrickson M, 2001; Nicholas et al. 2007; Mcain et al. 2008; Ho and Robles, 2011; Dorfman et al. 2013; Mulkins et al. 2014, Jones et al. 2014) The efficacy of such modalities in providing pain relief has not been established and more rigorous studies are required using a randomised control trial design that uses a control group which does not receive the intervention.

Electrotherapy

There are several electrotherapy modalities available to treat pain. These are transcutaneous electrical nerve stimulation (TENS), laser, interferential therapy, shortwave diathermy and ultrasound. There is insufficient evidence that demonstrates efficacy of some of these modalities in pain; however, TENS has been used widely in the management of acute and chronic pain. TENS was thus chosen as the electrotherapy modality to focus on for this review. TENS is the modality recommended by guidelines and a significant amount of research has been done in the field of chronic pain using this modality (Dailey et al. 2013; Lauretti, Chubaci and Mattos, 2013; Pallett et al. 2014; Koke et al. 2015).

The electrotherapy modality of TENS has often been touted as a good pain management tool in chronic pain as it activates inhibitory pathways while decreasing central excitatory mechanisms (Dailey et al. 2013).The long term benefits of TENS however remain to be proven in research (Dailey et al. 2013 Lauretti, Chubaci and Mattos, 2013; Pallett et al. 2014 Koke et al. 2015). A significant reduction in pain of two points or more on a visual analogue scale (Koke et al. 2015) and a significant difference in pain and fatigue with movement (Dailey et al. 2013) have been reported in a chronic pain population of fibromyalgia patients. However, the data collection methods used in this study may have influenced the results. The six minute walk test used as an outcome of function was performed prior to measuring pain. This may have resulted in decreased stiffness which subsequently could have resulted in decreased pain (Dailey et al 2013).

The use of TENS during active movement was recommended in a review by Vance et al. (2014) on the use of TENS for pain control. The review further stated that dosage, placement of electrodes and tolerance to TENS were issues that warranted further investigation in research. Other factors found to be independently associated with continued TENS use at the six month follow up assessment are; higher expectations of pain relief, neuropathic pain and absence of severe pain (Koke et al 2015). This may imply that an expectation regarding pain relief could affect outcomes of pain relief from TENS and that pain severity may play a role in determining efficacy of TENS in the management of chronic pain (Koke et al 2015). It is useful to note that those suffering from neuropathic pain were found to have continued the TENS treatment at the six month follow up assessment (Koke et al 2015). This may indicate that they found the treatment beneficial and this may be a management option for PLWHA who suffer from neuropathic pain. However, the long term efficacy of TENS in chronic pain remains unproven (Dailey et al. 2013; Lauretti, Chubaci and Mattos, 2013; Koke et al. 2015).

An observational study by Pallett et al. (2014) looked at compliance with TENS and the effect of TENS on pain intensity in patients with chronic low back pain. Pain intensity was measured at 4 time points on a daily basis, before, during, and at the end of treatment and 30 minutes after. Only 1 study participant complied fully with the TENS protocol and 20% showed good compliance. The majority of participants (77%) showed partial adherence to study protocol. However, 42% of participants responded to TENS treatment with a more than 30% reduction in pain intensity which is clinically significant according to IMMPACT recommendations (Dworkin et al. 2008). Of these only 29% utilised TENS for the prerequisite hour (Pallett et al. 2014). The researchers concluded that perhaps the inconsistency of efficacy that is reported in research for TENS can be attributed to participants not following the protocol of use correctly. This would mean that TENS is an effective pain management modality if used appropriately. Adherence is an aspect difficult to control as the implementation of pain management with TENS is mostly patient administered and relies on good patient education and compliance for correct implementation.

Studies reviewed in this section also differed in the treatment parameters set for use of TENS and due to a lack of standardisation in protocol, the comparison of the treatment outcomes is difficult. The periods of application and follow up varied ranging from seven days to four weeks of application and zero to six months for follow up post intervention. This makes it difficult to judge the long term efficacy of TENS reported as well as the optimum treatment time (Lauretti, Chubaci and Mattos, 2013).The use of TENS also carries a significant cost and may not be accessible to those with a lower socioeconomic status. This is unfortunately the case with a large number of PLWHA in South Africa. The use of TENS as a viable modality for pain management in PLWHA in South Africa is possibly not a realistic option.

The treatment modalities reviewed above are passive in nature and do not promote active engagement in an individual living with HIV/AIDS. Therefore, self-management of the disease may be compromised in individuals who use these modalities as treatment. They may be using passive coping strategies as opposed to active coping strategies to cope with their disease and symptoms. Passive coping strategies have been shown to demonstrate poorer long term outcomes in chronic diseases. Several studies reviewed under self-management and exercise sections below show that once individuals engage in active coping and management strategies of their chronic disease, their management of symptoms and health status improved. Another barrier to the use of these modalities is the costs of these modalities which restrict use to those who can afford the treatment. Access to this type of treatment is also not freely available in the rural areas of South Africa due to availability of

experienced therapists in these areas. We have a lack of healthcare resources in South Africa thus optimum service delivery is compromised. Using a self-management approach with active coping strategies will help to alleviate the burden on an already strained healthcare system. In addition this approach is cost effective as the affected individual spends less time attending treatments by different healthcare providers.

Education

Patient education, particularly pain neuroscience education, has recently been demonstrated to be an effective therapeutic tool in the management and prevention of pain (Furnes, Natvig and Dysvik, 2014). Education self-management programmes have been researched in the HIV population for many years (Gifford et al. 1998; Gifford and Sengupta 1999; Webel A R, 2010). Understanding how to manage the symptomatology, side effects and possible co-morbidities that accompany the diagnosis of HIV is vital to good medical management of the disease process for both the healthcare practitioners and PLWHA. Webel (2010) tested the efficacy of education alone on symptom management and medication adherence in PLWHA. No significant changes were found in medication adherence or quality of life outcomes. The weakness of this study, however, may lie in the scripted intervention. Whilst it standardised the process of education, scripted interventions do not allow for spontaneous group interaction and communication. Furthermore, at baseline the group had various co-morbidities which included depression and diabetes; all participants were female with four transgender females present (Webel A R 2010). These may have been confounding variables that could have influenced the study results. The participants also reported a low number of symptoms at baseline (0.49) on the HIV Sign and Symptom Checklist, thus a further reduction in symptoms may not have been reflected due to a floor effect. The qualitative comments of the participants, however, showed that they did experience benefits from the education as demonstrated by the two quotes below:

[“I like the program because I have learned more ways to control any negative symptoms I have.”] suggesting a gain of useful knowledge and [“I meet other women who are just like me and we learn about each other; they bring experience and they bring lots of information about HIV.”] which confirms the therapeutic nature of a group educational intervention (Webel A R, 2010, p 1033).

Two of the studies using education in PLWHA involved the same intervention called the positive self-management program (PSMP). The methodology differed in that one was a qualitative study using telephonic interviews with 24 participants who had undergone the programme (Gifford and Sengupta, 1999) while the other was a pilot of a randomised trial

done with 71 participants randomly allocated to a control group of usual care and the PSMP (Gifford et al. 1998). The qualitative study revealed positive feedback by participants similar to Webel's (2010) results. Five main themes were identified, these were: contracting which included setting of goals, use of the resource manual provided, support experienced by group members, knowledge and experience available in the group and a change of attitudes and behaviours (Gifford and Sengupta, 1999). Once again the study participant's comments revealed how helpful they found the intervention for goal setting:

["I guess probably the fact that even though you're really ill and you might have a life-threatening illness, you can still set goals and those goals don't have to be long-term goals. They can be short-term goals, but they kind of give you hope and give you something to work for. I thought that was beneficial."]. (Gifford and Sengupta, 1999, p 124).The benefits of the group communication with a group of participants who share a common illness are also demonstrated by the following statement:
["You know, it's like everybody comes to this [PSMP] at a different point and is at a different stage [of their illness], but we're able to build understanding and communication through that'] (Gifford and Sengupta,1999, p 126). The quantitative study reported a decrease in symptom severity and improved self-efficacy for control of symptoms in the intervention group while the control group (usual care) experienced an increase in symptom severity and a decrease in self-efficacy over a three month period (Gifford et al.1998).

These studies are supported by other research that shows that education may be effective as part of a self-management programme to improve symptom severity including pain and self-efficacy in chronic pain populations including PLWHA (Lorig et al. 1999; Lorig et al. 2001; Kravitz et al. 2011; Nkhoma, Seymour and Arthur, 2015).

Exercise

Exercise contributes to overall well-being by improving cardiovascular fitness, flexibility, muscle strength and endurance (Cassato and Churilla, 2009; Pedersen and Saltin, 2015) and has also been found to reduce the risk of chronic low back, neck and shoulder pain (Nilsen, Holtermann and, Mork, 2011). In addition to preventing health conditions, exercise and graded physical activity has also been shown to reduce pain scores in a chronic pain population (Gazzi Macedo et al. 2012; Tse, Wan and Ho, 2011). A study by Tse, Wan and Ho (2011) showed a reduction in pain scores on a 10 point scale of 2 points with a significant increase in range of motion ($p<0.01$) following an eight week exercise programme (including stretching, strengthening exercises and massage) in a cohort with a 73% prevalence of chronic pain. The reduction in pain was attributed to the exercise programme; however, the

massage component may have been a confounding variable in this study (Tse, Wan and Ho, 2011). A comparative study between motor control and graded exercise programmes which included stretching, strength and cardiovascular training supported Tse, Wan and Ho's (2011) finding in a population of chronic low back pain outpatients attending physical therapy in Australia (Gazzi Macedo et al. 2012). Although no differences were found between the control and experimental groups, all study participants experienced a significant reduction of two points on the numeric rating scale for pain, a reduction of disability and an increase in function as measured by the 24-item Roland-Morris Disability Questionnaire and 36-Item Short-Form Health Survey at 12 month follow up (Gazzi Macedo et al. 2012). The study results may be due to the effects of research study participation. This is due to the fact that both the control and experimental group improved regardless of the exercise intervention. The non-specific effects of any therapeutic relationship that may have developed between study participants and the researchers cannot be ruled out as a confounding variable.

The use of exercise as a non-pharmacological intervention has been demonstrated to improve the health of people suffering from chronic conditions such as diabetes and hyperlipidaemia (Pedersen and Saltin, 2015). HIV has evolved into a chronic disease much like diabetes due to the advent of antiretroviral drugs (Van Olmen et al. 2012). Early reports suggest that improved cardiovascular fitness, self-efficacy, weight, body composition, fatigue, health related quality of life and life satisfaction are benefits of exercise in HIV populations (Fillipas et al. 2006; Gomes et al. 2010; Smith BA, 2001. Two systematic reviews by the same group of researchers looked at aerobic and progressive resistive exercise and found exercise to be safe and beneficial for PLWHA in terms of improved cardiopulmonary fitness, body composition, psychological status (O'Brien et al. 2010) and improved weight and strength (O'Brien et al. 2008) respectively.

These reviews are supported by Gomes et al. (2010) who used an exercise programme that included cardiovascular, strengthening and flexibility exercise three times a week on alternate days over a period of 12 weeks in PLWHA. The study outcomes showed no significant changes in the CD4 count compared to baseline measurement but a significant increase ($p=0.002$) in self-reported life satisfaction using the Life Satisfaction Index (Gomes et al. 2010) . Further, Fillipas et al. (2006) compared aerobic and resistive exercises twice weekly to a walking home programme over a period of six months. The study outcomes showed an increase in self-efficacy, cardiovascular fitness, overall health and cognitive function for the exercise group when compared to the baseline scores and the control group scores (Fillipas et al. 2006). These results are further supported by a Zimbabwean study which looked at the effect of a 12 week progressive resistive exercise programme on health

realted quality of life in a cohort of PLWHA. The results showed a significant improvement in scores on the Euroqol 5D visual analogue scale for the intervention group (Mkandla; Myezwa and, Musenge, 2016).The long term efficacy of the interventions used in the above studies could not be established as the participants were not followed up post intervention (Fillipas et al. 2006; Gomes et al. 2010). Mkandla; Myezwa and Musenge (2016) also reported a high drop out rate of 60% which may have influenced the study results (Mkandla; Myezwa and Musenge, 2016).

Home programmes may be used to ensure carryover of benefits obtained during exercise programmes run in the clinic i.e the home programme will follow on from a supervised exercise programme done in therapy. Unsupervised exercise has been shown to be less effective than supervised exercise. This was demonstrated by the Fillipas et al.(2006) study results where an unsupervised home based walking programme had poorer outcomes than the supervised exercise group in spite of the high rate of exercise adherence by both groups.

The various studies discussed in the section above show that exercise has several benefits for individuals suffering from chronic pain and from HIV. Therefore, this may be a viable, cost effective intervention for the management of pain in PLWHA.

Self-Management

Self-management, in the context of a long-term medical condition, is defined as: ["Self-management is about giving people living with long-term conditions the tools, skills and support they need to improve their own wellbeing."] (selfmanagement uk 2015). Self-management may be an effective way of delivering a number of interventions to an individual in a manner that saves on resources and time spent. These skills can be initially taught by a trained peer leader or healthcare provider in a group setting. The individual then takes responsibility for their own disease management with home programmes or home based tasks which help them to put these skills into practice (Lorig et al. 1999). As discussed earlier, group therapy may be beneficial as it allows engagement in a group of peers which helps individuals suffering with the condition (such as pain or HIV or both) due to the support, trust and feeling that someone else understands their experience (Molassiotis et al. 2002; Haraldseid, Dysvik and Furnes, 2014; Furnes, Natvig and Dysvik, 2014) .

Lorig (1999) and colleagues originally presented the concept of self-management in a population of individuals suffering from a variety of chronic diseases (Lorig et al. 1999). This model has since been tested in a variety of settings with a number of chronic conditions such as arthritis, cancer, diabetes, heart and lung disease and HIV (Gifford et al.1998; Lorig et al.

2001; Gitlin et al. 2008; Kravitz et al. 2011). The positive effects achieved are not always maintained, for example the reduction of pain was not sustained post intervention when measured at 6 and 12 weeks in the study by Kravitz (2011) in a cohort of cancer pain sufferers. This could possibly also be due to the fact that the intervention was done in one visit and the follow up period was short.

Self-management has been used successfully to manage chronic pain in PLWHA and has been shown to reduce symptom severity and improve self-efficacy (Millard, Elliott and Girdler, 2013; Parker, Jelsma and Stein, 2016[a]). These results have shown short term efficacy as most studies used a 3 month follow up period as reviewed by Millard, Elliott and Girdler (2013), however, not all studies have rendered positive results. A small pilot study showed no significant changes in pain, fatigue and psychological symptoms (Gifford et al. 1998). The small sample sizes as well as the voluntary nature of the study (participants were recruited through public service announcements and advertisements) have contributed to some study bias and the lack of specificity of the pain outcome measure may have contributed further to this (Gifford et al. 1998). Another study in a cohort of chronically ill individuals (suffering from lung disease, heart disease or arthritis) also showed no significant effects for the chronic disease self-management programme developed by Lorig (1999) and colleagues. The researchers concluded the good healthcare that the control group received as usual care may have impacted on the study outcomes. These participants were also recruited through public advertisement though some were invited personally through outpatients' clinics (Elzen et al. 2007).

A framework for the components of a self-management programme in PLWHA has been proposed by studies reviewed (Lorig et al. 1999, Parker, Jelsma and Stein, 2013, Parker, Jelsma and Stein 2016[a]; Webel A R, 2010). The suggested components of a programme include education on HIV, nutrition, exercise, goal setting, action planning and problem solving in a group setting (Webel A R, 2010; Parker, Jelsma and Stein 2016[a]).

An example of a South African HIV self mangement programme is The Positive Living Programme (PLP) which was developed by Parker, Jelsma and Stein (2016[a]). It comprises a 6 week self-management programme that is accompanied by a detailed education manual. The programme is facilitated by a peer leader who was trained by the researcher. The training involved facilitation of a self-management group according to the information in the manual. The information in the manual covers a variety of topics pertinent to PLWHA. Self-management, exercise, symptom management, pain management, stress management and nutrition are outlined in the manual and faciltated by the peer leader during group sessions that are held on a weekly basis. Emphasis is placed on goal setting, problem solving and

active engagement of all participants to ensure the development of active coping strategies in management of HIV as well as pain. The programme is based on the chronic disease self- management programme developed by Lorig (1999) and colleagues and the subsequent studies on this model of self-management (Lorig 1999; Lorig et al. 2001). HIV is a chronic disease as discussed earlier in this review, thus it makes sense that a chronic disease self- management framework would be beneficial in managing the symptoms of HIV which include pain.

The programme was initially tested in a group of amaxhosa women in an urban setting and found to be beneficial in reducing pain severity, interference and improving self-efficacy, health related quality of life and depressive symptoms (Parker, Jelsma and Stein, 2016 [a]). The programme was compared to the education manual alone and both the control and experimental groups improved thus it is not clear what facilitated the improvement in participants. The study also had a short follow up period of 16 weeks. Further research is required to establish permanance of the effects and the link between the reduction in symptoms and the PLP.

The use of Peer Leaders in self-management groups

The use of peer leaders in facilitation of self-help groups is supported by research. Peer leaders have often been used in a variety of self-management programmes for chronic diseases such as diabetes, hypertension and HIV (Foster et al. 2007; Webel A R 2010; Mosack et al. 2012; Tang et al. 2014; Parker,Stein and Jelsma, 2014; Liu et al. 2015; Lorig, Ritter and González,2003). They are often utilized to address cultural and languange barriers in specific patient cohorts and to provide models to group participants or peers of how to manage medical conditions sucessfully(Parker,Stein and Jelsma, 2016[a]; Lorig, Ritter and González, 2003). There have been varying results in research reported which may to due to the different formats used in self-management groups. An example of this is Webels' (2010) study which used a scripted intervention. This could be identified as a possible confounding factor as it did not allow peer leaders to interact freely with group participants to facilitate learning.

A Chinese study reviewed earlier by Molassiotis et al. (2002) compared group CBT to a peer support counselling group and found that the peer support group's psychological well being improved and was maintained at three months following the intervention while the CBT group participants had short term improvements that did not last post intervention (Molassiotis et al. 2002). The follow up period for this study was limited to three months which does not demonstrate whether this would be an effective intervention in the long term.

Long term effects were demonstrated by another study which compared peer leaders and community health workers in a diabetes self-management programme. The study found that the participants in the peer led group had improvements in health outcomes that were sustained at 18 months when compared to the other intervention group. The authors argued that participants may have identified more strongly with a peer leader as the peer leader is suffering from the same medical condition and has to face similar daily challenges (Tang et al. 2014). This is a valid point and is specifically relevant in PLWHA who have to deal with the additional burdens of stigma and disclosure of their HIV status. The intervention in this study was, however, biased towards telephone based interaction as participants had difficulty travelling to the group sessions. One can therefore not assume that the same effects would be possible in a group face to face intervention which is the format for most peer led self-manangement programmes.

A cochrane review on the use of peer led self-manangment programmes in 7442 participants concluded that there is insufficient evidence to support an improvement in outcomes for longer than six months. Studies reviewed did show improvements in pain, disability, fatigue, depression, self-efficacy, self-reported exercise and reduced health distress but none of these were evaluated long term and the effects although significant were small. There was also no evidence to demonstrate that peer led interventions were superior to profession led interventions (Foster et al. 2007). Limitations of the review are that the majority of participants were women aged between 40-65 years so results should be restricted to this cohort and the research reviewed may be outdated as it was all prior to 2007. Further research is necessary to establish the efficacy of using peer leaders in self- management interventions. The obvious benefits of cost effectiveness and reduced strain on healthcare resources is particularly relevant in the South African context (Cobbing, Hanass-Hancock and Deane, 2014; Chetty and Hanass Hancock, 2016) where healthcare resources are limited for the population requiring healthcare.

The role of the therapeutic relationship in treatment

The reduction in pain intensity and interference in participants has often been attributed to non-specific effects or the placebo effect in the chronic pain population according to pharmacological studies (Moore et al. 2015; Dinat et al. 2015). Numerous drug trials for the treatment of neuropathic and chronic pain have failed to demonstrate drug efficacy due to placebo responses (Moore et al. 2015; Dinat et al. 2015; Fallon et al. 2015; Malik et al. 2015).

The effect of a therapeutic relationship on pain has been investigated previously and found to be distinct from the placebo effect (Kaptchuk et al. 2008). Studies reviewed earlier on complementary medicine demonstrated that patients who feel “cared for” within a therapeutic environment experience pain relief (Mulkins et al. 2014). This is supported by a study that examined the therapeutic alliance between physiotherapists and patients with chronic low back pain. Results showed that using an enhanced therapeutic relationship resulted in an average decrease of pain by 3.1 points on a numeric pain rating scale (Fuentes et al. 2014). This is a significant finding as it demonstrates that the use of empathy, warmth, caring and understanding within a therapeutic relationship can result in profound clinical effects such as the reduction of pain (Fuentes et al. 2014).

Pain associated with HIV also appears to be reduced when patients feel that somebody cares (Parker, Jelsma and Stein,2016[a]). The reduction in pain could be attributed to the “care effect” of having someone who cares about your pain and how you are feeling. In this study the participants were given the chance to attend a peer led group where they received support from fellow group members and the peer leader. The control group in this study did have access to the education manual; however, they did not receive active facilitation of the information in the manual. The results showed a significant decrease in pain in both control and intervention groups when compared to the usual care that the participants had received in the 15 months prior. In addition, there was an improvement in health-related quality of life, symptoms of depression and self-efficacy once pain had improved, in both groups. The role of the therapeutic relationship is unclear in this study as the control group had access to the education manual in addition to interaction with the research assistant with whom a therapeutic relationship was developed and thus the effect of the therapeutic relationship alone was not isolated.

The role of social support given by a healthcare provider may have an effect on the individual’s health related quality of life (Fuentes et al. 2014). This effect may help to partially counteract the negative support or social undermining that individuals experience due to stigma and social isolation associated with HIV (Maree, Dreyer Wright and Makua 2013; Parsons, Bond and Nixon, 2015; Denis P 2016).The role of the therapeutic relationship is thus important in providing support to those PLWHA who suffer from chronic pain as this additional support from a healthcare provider may assist in alleviating pain in these individuals. This has to be established in studies that examine more specifically the effect of the therapeutic relationship on pain. Ideally this needs to be done in a randomized controlled trial to establish if it is indeed the therapeutic relationship that is responsible for the changes reported by the studies above.

1.2.4 **Conclusion**

Pain is highly prevalent in PLWHA and is responsible for a high level of morbidity as it significantly affects quality of life and function (Hughes et al. 2004; Astoro et al. 2007; Van As et al. 2009; Balderson et al. 2013; Merlin et al. 2013). As the treatment of HIV has evolved, HIV is now viewed as a chronic disease (Van Olmen et al. 2012) that can be managed medically through the use of ARV's. However, management of pain experienced in this population is still problematic. There are a few studies that demonstrate that usual medical interventions have failed to manage pain effectively (Abrams et al. 2007; Frich and Borgbjerg, 2000; Koeppe et al. 2010; Dinat et al. 2015) .

There is a dire need to address the problem of pain in the HIV population as it has been shown to negatively affect quality of life (Hughes et al. 2004; Astoro et al. 2007). Self-management through the use of non-pharmacological interventions outlined above such as exercise, education and problem solving may be the answer with evidence that these approaches work in other chronic disease populations (Lorig et al 2001, Foster et al. 2007; Webel A R 2010; Millard, Elliott and Girdler, 2013; Furnes, Natvig and Dysvik, 2014; Parker,Stein and Jelsma, 2016[a]).

However, healthcare resources are often limited (Cobbing, Hanass-Hancock and Deane, 2014) due to the overloaded public healthcare system that most HIV sufferers have access to in South Africa (Cobbing, Hanass-Hancock and Deane, 2014; Chetty and Hanass Hancock, 2016). An innovative and cost effective approach is necessary when considering the management of chronic pain for PLWHA in South Africa. It is therefore important to establish whether a relatively resource intensive peer-led programme of self-management (Positive Living programme) recommended by Parker, Jelsma and Stein 2016[a] is more effective than simple educational resources or a therapeutic relationship.

This prospective study examined whether these approaches of peer led self-management or education were effective interventions for reducing pain intensity as a primary outcome and also improving the secondary outcomes of health related quality of life, self-efficacy, physical function and depressive symptoms in PLWHA who have chronic pain.

The aims and objectives of this study were therefore to measure the effects of:

- a therapeutic relationship compared to
- education together with a therapeutic relationship compared to
- a peer-led intervention (Positive Living programme) (Parker R E 2013, Parker, Jelsma and Stein 2016[a]) together with a therapeutic relationship,

In an urban cohort of PLWHA who suffer from chronic pain with respect to the following outcomes:

1. Pain severity measured with the Brief pain inventory (BPI)
2. Pain interference measured with the Brief pain inventory (BPI)
3. Depression measured with the Beck Depression Inventory II (BDI)
4. Self-efficacy measured with the Stanford Chronic disease 6 – item self-efficacy scale (SE6)
5. Health related quality of life measured with Euroqol 5D (EQ 5D)and
6. Physical function measured with the Simmonds battery

The null hypothesis of the study is: There will be no differences in pain severity or pain interference, health related quality of life, self-efficacy, depression and physical function in the participants in any of the three allocated intervention groups.

Chapter 2 Methods

2.1. **Research Design and overview**

This study was conducted at the Virology Clinic at the Charlotte Maxeke Johannesburg Academic Hospital. This is an outpatient clinic that is open weekdays from 8am to 1pm. The clinic services the geographical area around the Charlotte Maxeke Johannesburg Academic Hospital. Attendance at the clinic is approximately 95 patients per day. The study was conducted from August 2014 to December 2015. A sample of 70 participants was recruited from the queue at the Virology Clinic. People waiting in the queue to see the doctors were asked if they had pain over the last 3 months and if so, if they would be willing to participate in the study. Participants were taken individually to a consulting room in the clinic where the study was explained in more detail by the research assistants who spoke the local languages and assisted in obtaining informed consent. On confirmation that they met the inclusion and exclusion criteria and understood the nature of the study, written informed consent was obtained. The research assistants had worked in the clinic on previous occasions and were familiar with how the queuing system worked. They identified the patients on either side of the participating patient and their place was kept when they left the queue to participate in the interview for consent purposes. Thereafter they returned to the queue and came back to the study room for their baseline assessment when they had finished with their doctors appointment. On follow up visits the patients arrived to see only the research assistants for reassessment therefore there was no need to keep places in the doctors' queue for them.

Ethical clearance was obtained from the Human Research Ethics Committee (Medical) of the University of Witwatersrand. The ethical clearance number is M140877 (Appendix A). The trial was registered with the Pan African Clinical Trial Registry (PACTR) and the registration number is PACTR201410000902600 (Appendix B). The study followed an experimental comparative group design which included components of randomization and blinding.

2.2 **Sample Size Calculation**

The sample was calculated using the improvement of 3 points for pain severity in the brief pain inventory questionnaire with an alpha value of 0.5 to give the study a power of 90% if a sample of 20 per group is used thus a total sample size of 60 was required. The effect size was obtained from the previous study done (Parker, Jelsma and Stein 2016[a], Parker RE 2013). The sample calculation table is attached (Appendix C). Due to the drop out of participants, a modification and extension application was submitted to the Human Research

Ethics Committee (Medical) of the University of Witwatersrand to recruit an extra ten participants (Appendix D)

2.3 Randomisation of the sample

The researcher (DD) allocated participants to the three different intervention groups based on a randomization table obtained from a random number sequence generator at. https://www.random.org (Appendix E). A random number sequence was generated from 1-60 and 61-70 for allocation to three Groups namely: education, peer led self-management group and therapeutic relationship (Appendix E). Using these group allocations each participant was allocated a study number to ensure confidentiality and this number specified which group they were then allocated to. DD then set up appointments for the week 0 assessment and interventions depending on this allocation. An extra 10 participants were recruited later on in the study to counteract the effect of the large dropout of participants experienced. A second randomization table was generated for a further ten participants from 61 to 70.

2.4 Blinding of the sample

DD was responsible for ensuring blinding throughout the study. The research assistants were blinded to the group allocation of each participant. This was maintained by informing the participants and research assistants alike not to discuss group allocation or interventions with each other. All questions and queries with respect to interventions and the information provided in the education manuals were addressed by DD. The research assistants did not have access at any point in the study to the random number sequence table and specific group allocations. Furthermore, the research assistant's role was restricted to the administration of follow up assessments which were standardized and the same for all participants regardless of group allocation.

Recruitment of participants took 3 months pre-intervention. Once sufficient participants were recruited to run a peer led group a start date was booked and the participants allocated to this group were called to come in for the week 0 assessment prior to the start of the peer led intervention. All groups were assessed at week 0 and reassessed at week 4, week 8, week 12 and week 24 (Figure 2.1). Group 2 underwent a 6 week group intervention between weeks 0 and 8.

Each of the components in Figure 2.1 below i.e. recruitment and screening, interventions and follow ups will be dealt with now. Randomisation has been outlined earlier.

2.5 Screening procedure

DD and research assistants used the screening question taken from the Brief Pain Inventory: "Throughout our lives most of us has had pain from time to time such as minor headaches, sprains and tooth aches. Have you had pain other than these everyday kinds of pain during the last week?" to establish which of the patients qualify to participate in the study. This question was modified to include the "last 3 months" not "last week" as the study investigated chronic pain not acute pain. Anybody answering this question positively was invited to participate in the study. They were then given detailed information on the study (Appendix F) and informed consent (Appendix F) was obtained by the research assistants.

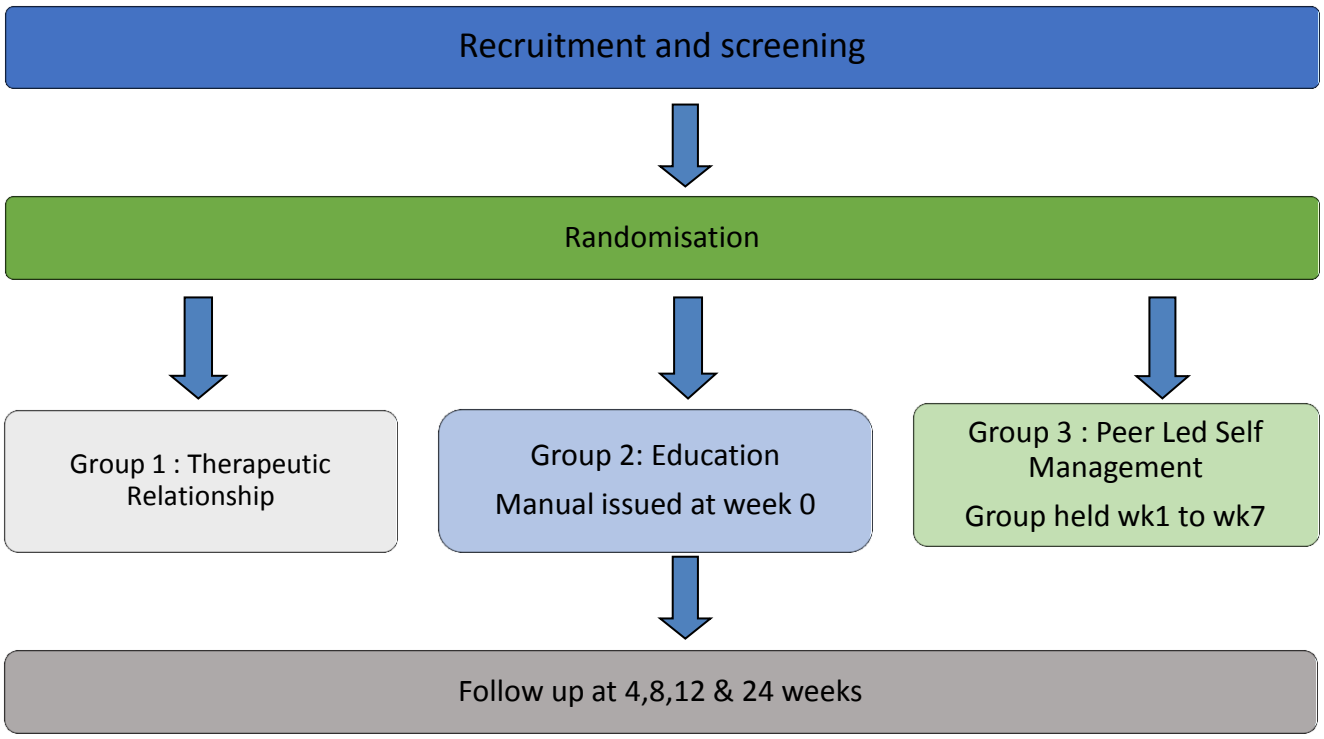

Figure 2.1 Study Design

2.6 Criteria for selection

The inclusion criteria for the study were as follows:

1. Age of participant had to be between 18 -40 years old
2. A confirmed diagnosis of HIV infection
3. On a stable highly an active antiretroviral treatment (HAART) regimen ≥ 6 months
4. ≥3 month history of pain

5. First and second language isiZulu speakers

The reason for including only those participants on a stable HAART regimen was to ensure that all participants were medically stable and on appropriate treatment with no other co-morbidities that could be confounding factors in the study.

A 3 month or more history of chronic pain was necessary to ensure that the participants who were recruited to the study were experiencing chronic pain (Merskey and Bogduk, 1994). Participants were required to complete questionnaires and potentially complete an intervention that included an exercise component, participants were excluded if:

1. they had any mental incapacity (defined as an inability to comprehend basic questions or information given about the study during recruitment)
2. they were non-ambulatory participants who did not fulfil ACSM Health/Fitness Facility Pre- participation Screening Questionnaire criteria (Appendix G)

Prior to study commencement DD, peer leaders and the research assistants all underwent training in the administration of the interventions, study methodology, research questionnaires and physical assessment batteries used.

2.7 Training

2.7.1 Researcher

I underwent training in Cape Town with my co-supervisor, A/Prof R Parker, the developer of the Positive Living manual (Appendix H) and the group intervention protocol, prior to commencement of the peer-leader training. The training took place over two days.

2.7.2 Peer leaders

Two peer leaders (one male, one female) were sourced from the Treatment Action Campaign organization. This is a non-profit organization run mostly by volunteers which works toward improving the healthcare of PLWHA in South Africa. The peer leaders were selected after interviewing several candidates for suitability. The peer-leaders were trained by DD for a total 32 hours over a two week period prior to the study commencement. This included training on the content of the Positive Living manual as well as facilitation of group interaction with the group members. Emphasis was placed on using a facilitatory approach during the groups rather than a didactic one.

2.7.3 Research assistants

The research assistants underwent the Good Clinical Practice course for non-clinical support staff run by the Wits Health Consortium. The course was based on clinical practice guidelines and training in the process of clinical trials and the course content can be viewed on http://www.academicadvance.co.za/Portals/0/GCP%20Basic%202016.pdf .

Thereafter DD commenced training of the research assistants in administration of all outcome measures. This involved training them in practicing the administration of the questionnaires on each other and two work colleagues who spoke English as a second language. DD also trained the research assistants on the administration and recording of time taken to complete the Simmonds battery of physical tests. This was also done to ensure inter-rater reliability. Once the research assistants were confident in the administration of all questionnaires and the Simmonds battery of physical tests the recruitment of study participants' commenced. The scoring of all questionnaires and data capture of the results was done by DD.

2.8. **Study roles**

The roles of the researcher (DD), research assistants and peer leaders are described below.

2.8.1 **Researcher**

DD was responsible for the following tasks: randomization, study management, blinding of research assistants, training of research assistants and peer leaders, data capture and analysis. The randomization of participants to the intervention groups was carried out by DD once the research participants had been recruited and screened by the research assistants. This was done using a random number generator which was discussed earlier under randomization. DD was responsible for the management of the study, training of the research assistants and peer leaders, payment of transport costs, allocation of appointments and refreshments as well as ensuring that the research assistants were blinded to the specific group allocation of each participant. DD collated, captured, analyzed and prepared the data for publication.

2.8.2 **Research assistants**

The recruitment and initial screening of participants for participation was carried out by the research assistants. The week 0 assessment and all subsequent follow up assessments were also carried out by the research assistants who were blinded to the specific group allocation of each participant. Unfortunately, due to the workload of the research assistants they were not able to always see the same participant for follow up appointments as there were other studies running concurrently as mine.

2.8.3 **Peer leaders**

The peer leaders were recruited and underwent training in the peer led self-management group which is detailed in this chapter. The peer led self-management group lasted for 6 weeks and occurred between weeks 0 and 8. This was overseen and monitored by DD to ensure that the groups were run correctly. The supervision was done through briefing prior to sessions and debriefing after each session held. Peer-leaders were compensated for their time with an hourly stipend of R52.75.

2.9 Data Collection

A baseline measurement was administered to all participants at week 0. Thereafter, reassessment occurred during follow up visits at week 4, 8, 12 and 24 shown in figure 2.2. We recruited 50% of the peer led intervention participants, started the group intervention and then recruited the next 50% for the second peer led intervention group. All participants were recruited and randomly allocated as per the random number allocation tables described above. All research participants received reimbursement for travel and airtime to ensure that they could call DD in-between appointments if necessary. DD allocated the funding on every visit and sent reminder messages via cell phone to all participants a day before their appointments.

2.9.1 **Measurement tools**

The outcome measures used in the study were as follows:

1. The Brief Pain inventory (Short Form) (Appendix I)
2. Becks Depression Inventory II (Appendix J)
3. Euroqol-5D (Appendix K)
4. Stanford Chronic disease 6 – item self-efficacy scale (Appendix L)
5. Simmonds battery of physical tests (Appendix M)

These assessments were administered by the research assistants and will be discussed individually below with respect to their suitability for use in this study.

The Brief Pain Inventory (Short Form) (Appendix I)

The Brief Pain Inventory (BPI) is a self-report questionnaire that measures pain intensity and pain interference (Cleeland CS 1989). The BPI was originally developed for use in cancer pain and has since been validated for use in chronic non-cancer pain (Tan et al. 2004, Daut RL 1983). It is derived from an earlier questionnaire the Wisconsin Brief Pain Questionnaire

(WBPQ) (Daut RL 1983). It is an easy to understand scale that takes a fairly short amount of time to complete (10 minutes). The pain intensity questions use a numerical rating scale from 0 to 10, where 0 is labelled as "*no pain*" and 10 is labelled as "*pain as bad as you can imagine*". The questions rate the participant's worst and least pain in the last 24 hours, average pain and pain right now at the time of assessment. The participant then records the treatment or medication taken for the pain and rates how much relief these provide. Once again a scale from 0% to 100% is used where 0% indicates "*no relief"* and 100% indicates *"complete relief".* The pain interference items follow the same format using a numerical scale where 0 is labelled *"does not interfere"* and 10 is labelled *"completely interferes".* General activity, mood, walking ability, normal work, and relations with other people, sleep and enjoyment of life are the domains assessed for pain interference. Severity of pain is graded as follows: mild pain ranges from severity level 1 to 4, moderate pain ranges from 5 to 6 and severe pain ranges from 7 to 10 according to the scoring criteria of the BPI.

Since its development, the BPI has been used in a number of studies on HIV related pain (Merlin et al. 2012, Evans et al. 2003; Smith M Y, 2002, Uebelacker LA , 2015) including a few South African and African studies (Nkhoma , Seymour and Arthur, 2015, Wahab and Salami 2011). The WBPQ, the precursor to the BPI, was validated in three indigenous South African languages, namely, Isizulu, Setswana and Xitsonga. In addition it was also validated for use in second language english users(Mphahlele, Mitchell and Kamerman, 2008). When one compares the WBPQ and the BPI there are minimal differences. "Least" pain severity was added to the BPI and the interference by pain is described using visual analogue scales where as the WBPQ used a categorical rating scale and did not have a "least " pain severity category. In addition, the WBPQ asked about the type of pain and effectiveness of pain treatment and the patients perception of the cause of pain where the BPI asks about medication use and a rating of effectiveness is used (Cleeland CS, Brief Pain Inventory User Guide, 2009). Mphahlele, Mitchell and Kamerman (2008) found that the internal consistency of the items was good with the Cronbach alpha co-efficient ranging from 0.80 to 0.88 for pain intensity across the different languages. The study also found the Cronbach alpha co-efficient for pain interference ranged from 0.73 to 0.94. This study was completed in both urban and rural cohorts in a South African HIV positive population (Mphahlele, Mitchell and Kamerman, 2008). The BPI was also translated and validated for use in the isiXhosa language in an HIV positive population (Parker, Jelsma and Stein 2016[b]). For the current study the English and Isizulu versions of the BPI were used. Average pain severity was not included in my calculation of the pain severity score. A previous validation study of the BPI (Mpahlehle, Mitchell and Kamerman, 2008) showed that 'average' pain intensity did not translate well in isiZulu and that the term average pain

translated to ”medium”, “pain in between” or “mild” pain (Mpahlehle, Mitchell and Kamerman, 2008). Thus the average pain severity reported by amaZulu participants would not be an accurate reflection of their average pain (where average is the patients rating of pain that is felt for most of the time) and this would impact on the validity of the pain severity score making it an unreliable measure. In my study I therefore excluded average pain intensity when calculating the pain severity score to ensure a more reliable measure of pain severity.

The scale has demonstrated ability to detect improvement over time (Tan et al. 2004). It was chosen as it has been validated for use in chronic non cancer pain, has been used and validated in HIV studies, therefore, is appropriate for the study population chosen. The IMMPACT recommendations on outcome measures in chronic pain found that the pain interference scale of the BPI met the criteria for assessment of clinically significant differences in physical function (Dworkin et al. 2008). This lends weight to my choice of this outcome measure in this study.

Other instruments such as the Mcgill pain questionnaire (Main C J, 2015) were considered, however, the McGill pain questionnaire may not be understood well by participants who are using English as a second language (Main C J, 2015). A second limitation is it has not been translated into South African languages used in this study. Furthermore, The Mcgill pain questionnaire does not examine interference with daily activity which the BPI does. Therefore, the BPI was selected over the Mcgill pain questionnaire as the outcome measure of choice to measure pain intensity and severity. Permission to use the Brief Pain inventory was obtained prior to use in the study from Dr. Charles S. Cleeland.

Beck Depression Inventory (Appendix J)

The Beck Depression Inventory (BDI) is a self-report questionnaire that looks at depressive symptoms and has been revised several times (Beck et al. 1961). This study used the Beck Depression Inventory Version II which is the third version of the BDI (BDI-II manual 1996) English and Zulu versions**.** The items included are designed to correspond to the DSM IV diagnostic criteria for depression and it was originally validated on a population of psychiatric patients and normal adults (Beck et al. 1961). The BDI consists of 21 groups of 4 items that have a numeric rating of 0-3 rendering a total score of 63. The items are ranked from 0 to 3 on a Likert scale according to the degree of symptom severity experienced with 0 being no symptom and 3 being a severe degree of symptom severity. Item 16 and 18 pertaining to sleep patterns and appetite respectively have a 7 point scale to detect changes in behaviour to aid in diagnosis. The total score is divided into ranges for minimal (0-13), mild (14-19), moderate (20-28) and severe depression (29-63) (BDI-II manual 1996).The participants

report how they are feeling right now and the questionnaire consists of the following symptoms / behaviour associated with depression: mood, pessimism, a sense of failure, a lack of satisfaction, feelings of guilt, a sense of punishment, self-dislike, self-accusation, suicidal tendencies, crying, social withdrawal, indecisiveness, distortion of body image, work apathy, sleep difficulties, fatigue, loss of appetite, weight loss, loss of libido, preoccupation with somatic symptoms and irritability (Beck et al. 1961).

The BDI has been used in the chronic pain population (Beck and Steer, 1988; Kerns RD, 2004) and the IMMPACT recommendations (Dworkin et al. 2008) are for the use of the BDI to identify clinically significant differences in emotional functioning in chronic pain participants. Whilst Kerns (2004) reported that the BDI II may inflate depressive symptoms in people with chronic pain as it was not developed for use in chronic pain (Kerns RD, 2004), a consensus meeting addressing the use of outcome measures in chronic pain identified that small changes on the BDI were clinically meaningful (Dworkin et al. 2008). With its robust psychometric properties the BDI is recommended as an appropriate outcome measure of emotional functioning in chronic pain. It is suggested that three criteria could be used to measure clinically important change in participants who have chronic pain: the BDI score is considered normal if <10; if a shift occurs to a less severe category e.g. moderate to mild; if there is a change of 5 points on the BDI score(Dworkin et al. 2008).

The BDI II has been validated for use in a population of PLWHA (Lipps GE, 2010). It has also been used in studies with HIV related pain (Evans et al. 2003; Keltner et al. 2012) and in South African studies of PLWHA (Govender and Schlebusch, 2012; Nel and Kagee, 2013; Breet et al. 2014) though the studies were not pain related. The BDI II has been translated into isiZulu (Govender and Schlebusch, 2012) which makes it a good choice for this study as it allows for easier administration to participants in the South African setting where Zulu is spoken as a first or second language. As it has been used previously in studies with HIV related pain as well as South African PLWHA the English and Zulu versions of the BDI II was chosen as the outcome measure of depression this study. Permission was applied for and granted through www.pearsonclinical.co.uk.

Euroqol-5D (Appendix K)

The Euroqol 5D is a self-report questionnaire that measures the health related quality of life (HRQOL) of an individual (Brooks R 1996, Buxton et al. 1990). It has 5 dimensions which measure physical, social and psychiatric aspects. These aspects are assessed by rating mobility, self-care, usual activities, pain or discomfort, and anxiety and depression according to a 3-point scale that ranges from no problem to extreme impairment or severity. Thereafter

the participant then has to rate their state of health on a visual analogue scale from 0 to 100 with 0 being the *"worst imaginable state of health"* and 100 being the *"best imaginable state of health"* (Buxton et al. 1990).

This outcome measure was developed in Europe with several European countries participating in its development; however, its simple nature easily allows use in a variety of settings. The questionnaire was originally developed to complement other HRQOL instruments and give an indication of state of health (Buxton et al. 1990). The EQ 5D is short and easy to complete as it can be completed within 5 minutes. If compared to other health related quality of life scales such as the SF36, the EQ 5D yields information about quality of life in a much shorter and simpler format (Nilsson et al. 2007). This is helpful when the EQ 5D is used in populations that are second language English speakers or has to be translated for use in a different language as the terminology used in the questions is simple. This is also beneficial when used in a group that has a lower level of education such as the study participants in this study. Nilsson et al. (2007) found that a higher percentage of respondents found the EQ 5D easier to use than the SF36 and that satisfaction with both instruments was rated equally (Nilsson et al. 2007).

The Euroqol 5D has been validated for use in both an HIV (Wu et al. 2002) and chronic pain population (Hurst et al. 1997, Soer et al. 2002). It has also been used in previous studies on HIV related pain (Keltner et al.2012; Merlin et al. 2015). The EQ 5D was translated into isiXhosa (Mkoka et al. 2003) and validated in an urban Xhosa speaking population (Jelsma et al.2004). The EQ 5D was then used to assess HRQOL in a South African isiXhosa speaking population of PLWHA (Hughes et al. 2004). The questionnaire has been translated into isiZulu; however, no published validation studies could be found. IsiZulu is similar to IsiXhosa as they have a common root language (Nguni) and are thus likely to have similarities in their culture (Valchev et al. 2011). The EQ5D could thus be used with Zulu speakers as well. The above data and previous studies demonstrate that the EQ 5D is a user friendly outcome measure to assess HRQOL and has been translated into the South African languages used in this study. These were the reasons the English and Zulu versions of the EQ 5D was picked as the assessment of choice to measure HRQOL.

Stanford Chronic disease 6 – item self-efficacy scale (Appendix K)

The Stanford Chronic disease 6 – item self-efficacy scale (SE 6) is a self-report scale that looks at the measurement of self-efficacy in 6 domains (Lorig et al. 2001). These are: fatigue, physical discomfort or pain, emotional distress, symptoms or health problems, self-management tasks or activities and medication use. The scale is rated using a visual

analogue scale that ranges from "*1* (*not at all confident*) to 10 (*totally confident*)" (Lorig et al. 2001). The original scale had 33 items in 10 subscales but this was reduced to 6 items (Brady T J, 2011). All six items are added and the mean is calculated by dividing the total by six. This is then used as the self-efficacy score (Lorig et al. 2001).

This scale was developed by the Stanford Patient Education Research Centre from a number of self-efficacy scales developed for their chronic disease self-management programme. It was tested on 605 subjects with a variety of chronic diseases initially with a Cronbach alpha score of 0.91 (Lorig et al. 2001). A recently published study looked at the reliability and responsiveness of the SE6. The authors concluded that the scale could be used to assess self-efficacy in a number of chronic disease populations (Ritter and Lorig, 2014) which is relevant to this study of chronic pain in HIV. In addition, a review by Miles et al. (2011) noted that this scale along with the Pain Self-Efficacy Questionnaire (PSEQ) and the Chronic Pain self-efficacy Scale (CPSS) were suited for use in the chronic pain population. The SE6, was recently used in a South African study of HIV related pain (Parker, Jelsma and Stein 2016[a]) and has been used in studies of various chronic conditions (Griffiths et al. 2005; Lester, Stepleman and Hughes, 2007; Gitlin et al. 2008; Dal Bello-Haas et al. 2010; Freund et al. 2013) and spinal cord injury (Pang et al.2009) in various populations. Since HIV is now considered a chronic disease (as noted in Chapter 1), this scale was chosen to measure self-efficacy in the research participants in this study. The English and Zulu versions of the SE6 were used for this study.

Simmonds battery of physical tests (Appendix L)

The inclusion of physical exercise in the Positive Living manual and as part of the peer led group intervention links to possible improvements in physical function thus the Simmonds battery was chosen as an objective measure of physical function. The Simmonds battery consists of 9 subtests or physical tasks that the research participant must complete (Simmonds et al.1998). These include 3 walking tests (preferred speed test, fastest speed test and measurement of distance walked in 6 minutes), loaded and unloaded reach tests, belt tie, sock test, a reach up test and a sit to stand test. These are described in the table below (Table 2.1) the test battery was initially validated on a sample of low back pain participants and a group of healthy pain free participants (Simmonds et al. 1998).

The Simmonds battery has not been used in any published African studies using a HIV pain cohort but has been used in a study of ambulatory PLWHA who attended an outpatient facility in the United States of America (Simmonds, Novy and Sandoval, 2005). No published African studies in PLWHA to date could be found which included an objective measure of

function. The battery was included in my study's outcome measures to provide an objective measurement of the research participants' physical function which allowed comparison to self-reported physical function from the other outcome measures used.

At the time of data collection we noted that a separate study on a similar intervention with osteoarthritis patients found no significance differences between groups for the ability to don the sock or the time taken to don the sock during the sock test (Saw, M 2015). It was then decided that the sock test would be excluded from the battery when administering the Simmonds battery in my study. The removal of the test did not have an effect on the scoring of the test or the interpretation of the results as each subtest is scored and evaluated independently of each other.

Table 2.6 Description of Simmonds Battery

Simmonds Battery		
Subtest	**Description**	**Assessment**
Preferred walking speed	Participants walk 15 metres at their preferred walking speed.	Average speed of walking
Fastest walking speed	Participants walk 15 metres at their fastest walking speed.	Speed of walking
Distance walked in 6 minutes	Participants walk for 6 minutes measured in 15 metre laps.	Endurance and strength
Loaded reach	Participants stand adjacent to a wall where a tape measure is placed horizontally at shoulder height. The participant reaches forward as far as possible holding a 4 kilogram weight horizontally at shoulder height.	Endurance and strength
Unloaded reach	Participants stand adjacent to a wall where a tape measure is placed horizontally at shoulder height. The participant reaches forward as far as possible with no weight at shoulder height.	Range of motion of upper limbs
Belt tie	Participants sat in a chair and were timed as they wrapped a standard crepe bandage approximately 1 metre in length around their waist.	Co-ordination and speed of movement
Sock	Participants sat in a standard chair and were	Co-ordination and speed of

	timed as they put on 1 loose fitting sock.	movement
Reach up	The participant faced a wall and reached as high as they could with both hands which was measured in centimetres.	Range of motion of upper limbs
Repeated sit to stand	Participants were timed as they sat down and stood up twice a rest period was given between the first and second test. An average of both tests was used.	Speed, co-ordination and range of motion

2.10 **Interventions**

My study used three different interventions namely, the therapeutic relationship, education and a therapeutic relationship and the peer led self-management group which included education and a therapeutic relationship. These will be described further below.

2.10.1 **Group 1 – Therapeutic relationship**

This group of participants were assessed at week 0 then returned for follow up at week 4, 8, 12, and 24. In these appointments the outcome measures were repeated and the research assistant also asked culturally-appropriate questions, such as asking after the health of their family. During training of the research assistants, the researcher discussed the importance of forming a good relationship with participants by asking about their health and family prior to the commencement of the administration of questionnaires. A friendly, warm, open and empathetic manner of communication was encouraged by the researcher and this was continually refreshed and discussed with the research assistants throughout the data collection period. This was done in an effort to build and maintain a therapeutic relationship with all participants so that the effects of this relationship could later be seen in the study results.

2.10.2. **Group 2 – Education group**

This group included the therapeutic relationship explained above, with additional access to the educational material in the form of the Positive Living manual (Appendix M). The participants allocated to this group received educational material in the form of the Positive Living manual (Appendix M). The manual was given to these participants at week 0 after the baseline assessment by DD, to avoid any bias on the part of the research assistants who administered the assessments. This manual was translated into isiZulu and isiXhosa prior to

the start of the study and was also offered in English. The translation of the manual was done through the use of a reputable national translation company. The translation was carried out following a standard procedure with two independent language translators completing the forward translation of the manual into isiZulu and then two other language translators completing the backward translation into English. Thereafter a consensu meeting was held to discuss and agree on any discrepancies that arose in this process.

The manual contains education about self- management, exercise, stress management, nutrition, relaxation and symptom management and has been used previously (Parker R E 2013, Parker, Jelsma and Stein 2016[a]).To ensure that blinding remained, if the participant wished to ask questions on the information contained in the booklet they were directed to DD or to their treating health care professional i.e. doctor or nurse at the clinic.

2.10.3 **Group 2- Peer led self-management group**

The intervention included the therapeutic relationship explained above and a peer led multimodal group intervention. Participants were also given the Positive Living manual at week 1 of the intervention. This intervention was run over a period of 6 weeks and consisted of weekly peer led sessions with a group of participants. The sessions are outlined in the figure below (Figure 2.3). The sessions are based on the information in the Positive Living Manual (Appendix H) described above and given to the education group. The difference between the education and peer led group was that the information was facilitated by peer leaders in the peer led group.

The study on which the peer led group was based found that when the programme was reviewed, concerns were expressed by the reviewers (who were recruited from the community) about groups with mixed sexes. The reasons given for these concerns were that aspects such as sexuality were not discussed in a mixed sex group as it is not culturally appropriate (Parker R E 2013). Thus there was a need for single sex groups and two-peer leaders, one of each gender.

During the first session there was a discussion about the importance of confidentiality within the group and all participants signed an additional consent form that included consent to physical activity, consent to non-disclosure of information during the group, agreement to attend the weekly group session and the follow up appointments required for assessment.

The aims of the programme were to educate participants about self-management and facilitate the use of a self-management programme by participants. This would help participants manage their chronic pain, symptoms of HIV and any psychosocial

manifestations such as stress or depressive symptoms through the use of non-pharmacological interventions.

This group of participants was assessed at week 0 which occurred in the week of the first peer led group then returned for follow up at weeks 4, 8, 12, and 24.

The intervention consisted of weekly sessions of two hours each shown Figure 2.2 below and explained in detail thereafter. They were taken through the manual with facilitation by the peer-leaders. The facilitators were briefed prior to each session and debriefed after every session by DD, to ensure that the peer leaders facilitated the groups according to the protocols they were trained in.

The first week's topics of self-management and exercise explained the steps of self-management, the importance of exercise, what type of exercise to do and how to develop an action plan and achieve goals set each week. A simple exercise routine was demonstrated by the peer leader which was composed of 20 minutes of exercise. This was made up of 10 different exercises which included stretching and aerobic exercises such as marching on the spot. These exercises were repeated at each weekly session and participants were encouraged to do the exercises at home as part of their exercise goals.

Week 2 covered symptom management in general and then looked at specific symptoms and signs that PLWHA may suffer from. Action charts and checklists were used to help the participant understand the severity of the symptom experienced and whether this required the intervention of a healthcare professional or could be managed at home.

In week 3 stress management was examined and this included a long and short relaxation session that the participants were encouraged to do at home. The relaxation session was administered by the peer leader within the session thereafter it was included at the end of every group session. The script for the relaxation therapy was included in the education manual so that participants could use this to practice the technique at home. The practicing of the relaxation session within the group was done to facilitate the participants learning about the technique and becoming more skilled at it.

Pain management was the topic of week four with guidelines and suggestions of how to manage one's pain. Good nutrition and the safe storage and preparation of food were covered in week 5.

The last week was used to help participants plan for the future and ensure that they continued to use the self-management skills they had learnt so that they could manage their HIV and chronic pain experienced (Parker R E 2013, Parker, Jelsma and Stein 2016[a]).

Each week included a feedback session that focused on goals that had been set in the prior session pertaining to that week's topic, for example for session one- exercise – to walk every day at home for 10 minutes. The achievement of the goal was rated and if the goal was not achieved discussion around reasons for this and how these could be addressed differently next time was discussed.

Once the group had finished the six week programme the individual participants were asked to fill in a feedback questionnaire (Appendix N) given to them by DD. All participants were asked if they understood the questionnaire and DD and the peer leader were present if anyone required help understanding the questions, however, none of the participants requested assistance and all completed questionnaires were done independently by the participants. This questionnaire included the following questions:

1. What did you like about the course?
2. What didn't you like about the course?
3. Was there anything more you would like to learn that wasn't in the course?
4. What did you like about the workbook?
5. What didn't you like about the workbook?
6. Is there anything you would like to add or change in the workbook?

The information was then collated and the most common comments were noted. Each participant was also awarded a certificate of attendance at the end of the six week programme.

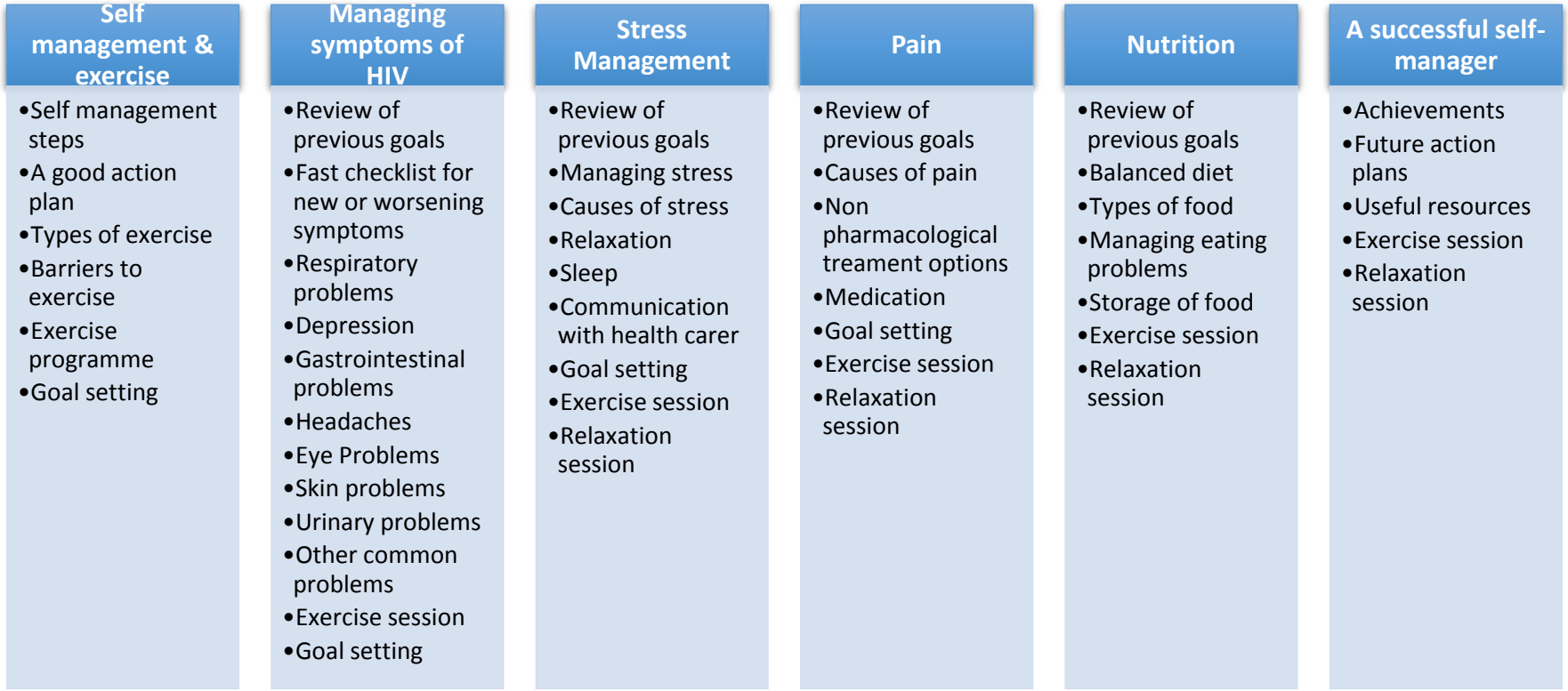

Figure 2.2 Outline of weekly sessions in the Positive Living Programme

2.11 **Data Analysis**

Once the data had been collected from the participants I entered the data onto an electronic data base system called Research Electronic Data Capture (RedCap 6.14.1 - © 2016 Vanderbilt University). This system allowed easy capture of the data collected onto an encrypted website that was password protected. Once the data had been entered it was exported to Microsoft Excel. The data were cleaned in order to prepare for statistical analysis. The statistical analysis was done using GraphPad version 6 (Graphpad, California) and R version 3.1.2 (R Core Team 2016). Normally distributed data were described using mean and standard deviations. Non-normally distributed data were described using median and range. Univariate analyses of dichotomous variables were carried out using a chi square test, parametric, continuous variables were compared using a one way Anova and non-parametric, continuous variables were compared with a Krushkal Wallis test.

There was missing data as participants did not attend all follow up visits. As a result, and because repeated measures needed to be taken into account, two way ANOVAs could not be used for multivariate analysis. A mixed model linear regression was used to fit a null model, which was then compared to models of the effects of group, time and group and time. When significance was found a correction for multiple comparisons was carried out using the Holm Bonferroni method. If models remained significant they were compared to each other using an ANOVA. If one model was no better than another, the simplest model i.e. the model with the fewest terms was chosen.

Prior to the linear regression, diagnostic tests were used to assess normality and heteroscedasticity of the data including histograms, quantile-quantile plots and graphing residual plots (Appendix O). Non-normally distributed data were transformed using log transformation or square root transformation as appropriate when non-normally distributed data couldn't be transformed successfully, a Friedman test was used to determine effects over time and a Kruskal Wallis test was used to determine effects between groups for the self-efficacy, sit to stand, reach up and belt tie tests to establish significance.

A p value of <0.05 was considered significant. Data were represented graphically using means and standard errors of mean.

I completed all univariate analysis. The mixed-model regression was carried out by A/Prof Peter Kamerman from the School of Physiology. Statistical procedure followed was an intention to treat analysis.

Chapter 3 Results

3.1 **Sample flow and demographic data at baseline**

The flow diagram below in figure 5 shows the flow of the sample from recruitment to the week 24 follow up visit. Initially 70 participants were approached, four were excluded (reasons given in flow chart below), 66 participants were recruited, a further 25(37%) of the sample were excluded from statistical analysis due to not returning for follow up after week 4 and not arriving for the first group session in the peer leader group. As a result there were data for 41 participants at week 0. At week 24, 28 participants remained with the majority of these allocated to the therapeutic relationship group (13). Some participants missed follow up visits but returned for the next follow up visit.

This loss to follow up over the 24 week period amounted to 32% of the sample (13/41) at baseline. This has been attributed to the finding of employment, relocation to other provinces and a loss of contact with participants. The total attrition from the initial sample recruited is therefore 58% as 38 participants were lost to follow up from the initial 66 participants. Various measures were undertaken to prevent the loss to follow up. Participants were sent reminder sms's for appointments and called when they did not arrive on the day. In addition they were called afterward to allocate a second appointment date and time and two contact numbers were taken at recruitment stage to ensure that the researcher could contact the participants. The only avenue not explored was the use of home visits when the participants did not arrive or were not contactable by numbers provided. This is an option that should be considered for future research undertaken in this setting.

I will describe the baseline characteristics and demographics of the sample outlined in Figure 3.1 below before explaining the results of the comparison of all variables and the results of the statistical tests used.

The participants of all groups at baseline assessment were fairly homogenous in composition as demonstrated in the table (Table 3.1) below. They were mostly composed of women with no significant difference in the gender composition between groups. The majority of the sample had a secondary school level of education and was unemployed. No significant difference was found for nadir CD4 counts, viral loads, time since diagnosis of HIV or ARV treatment. Most participants were on first line antiretroviral treatment.

Scores on the BPI, EQ5D, BDI and SE6 were also found to be fairly homogenous with no significant differences between groups at baseline assessment prior to interventions.

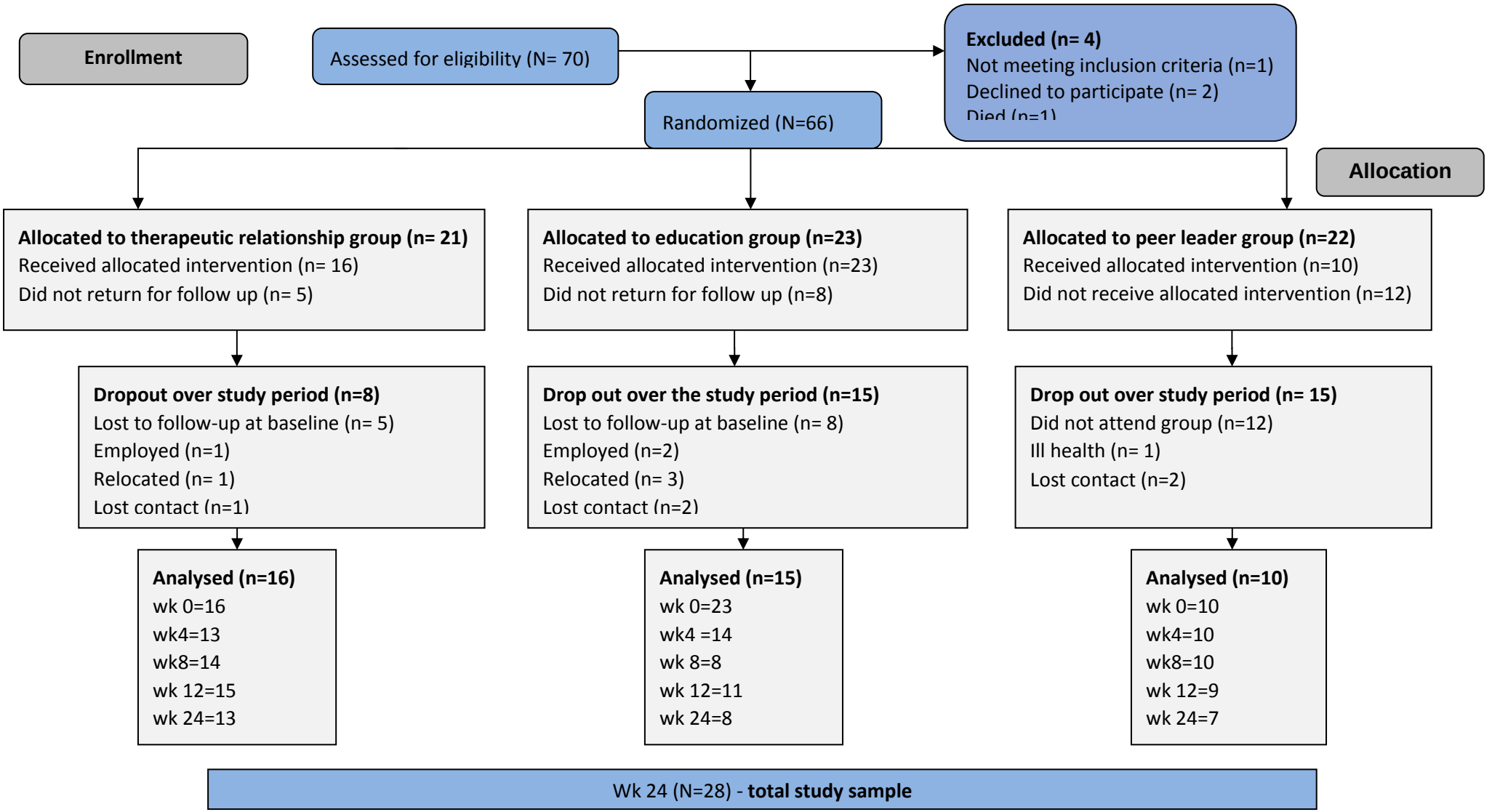

Figure 3.1 Flow diagram depicting research study

Table 3.1 Baseline characteristics of the sample

Age, sex, occupation, educational level, viral load and treatment is displayed using means and standard deviations [mean (SD)].				
Variables	**Therapeutic Relationship**	**Education**	**Peer Leader**	**p values**
Age in years	41(6)	37(5)	36(6)	0.79[e]
Sex Female Male	 12 (75) 4 (25)	 12(80) 5(20)	 6(60) 4(40)	0.46[d]
Occupation Employed* Unemployed**	 9 (56) 7(44)	 5(33) 10(67)	 3(30) 7(70)	0.35[d]
Educational Level None Primary Secondary Tertiary	 0 0 [a]16(100) 0	 1(7) 3(20) [b]11(73) 0	 0 0 10(100) 0	0.05[e]
Viral load copies/mL [c] LDL >LDL Missing data	 11(69) 5(31)	 12(80) 0 3(20)	 7(70) 3(30)	0.34[e]
Treatment 1st line ARV 2nd line ARV 3rd line ARV	 13(81) 2(13) 1(6)	 14(93) 1(7) 0	 8(80) 1(10) 1(10)	0.77[e]
EQ5D VAS, BDI scores, SE-6 scores, CD4 nadir and time since diagnosis is displayed using medians and ranges [median (range)].				
Time since diagnosis in years	8 (1-12)	6 (1-15)	6(2-14)	0.61[f]
CD4 Nadir in cells/mm^3	250(12-569)	125(11-366)	249(3-325)	0.16[f]
EQ5D VAS	60(20-90)	70(50-90)	60(20-80)	0.14[f]
BDI	17(8-25)	27(4-43)	20(4-49)	0.20[f]
SE-6	9(0-10)	9(0-10)	9(7-10)	0.91[f]

Employed** – consists of part time, temporary and full time employment,*Unemployed** – consists of unemployed, those on disability grants (n = 2) and student (n = 1),

[a] Included 2 participants with Early Childhood Development course, [b] Included 3 participants with courses done after secondary school, [c] Included missing data for 4 participants.

[d]**Chi square test** used to determine significance between groups, [e] **One way Anova** was used to determine significance between groups, [f] **Krushkal Wallis** was used to determine significance between groups

3.2 Baseline pain characteristics

The focus of this study was on non-pharmacological interventions for chronic pain in PLWHA thus it was important to examine the results of the BPI in detail. The baseline pain assessment results are outlined below (Table 3.2) and show that all groups had similar scores for pain severity and interference at baseline. The scores for pain severity ranged from a mild to severe level of 2 to 7. Pain interference was found to be moderately affected across all groups. Regarding analgesic use 44% reported no medication, 32% used paracetamol, 12% using amitriptyline, 5% ibuprofen, 2% aspirin and 5% other medication. For the 56% (23/41) using analgesics, pain relief reported from medication on average was rated as 39% on the BPI numeric rating scale where 0% indicates no relief and 100% indicates complete relief. Two sites of pain were commonly reported by participants with the most number of pain sites reported being seven. The five most common sites participants experienced pain were the feet (42%), chest (24%), lumbar (24%), ankles (24%), head (20%) and abdomen (18%). There were no significant differences found for the pain characteristics at baseline as shown below in table 3.2.

Table 3.2 Characteristics of pain experienced at baseline

Worst, least and current pain severity scores and all pain interference scores are displayed using medians and ranges [median (range)].				
Variables	**Therapeutic Relationship**	**Education**	**Peer Leader**	**p values**
Pain severity	5 (2-7)	5(2-6)	5(3-6)	0.09
Pain interference (average score)	5(0-8)	6(0-10)	6(0-9)	0.60
General activity interference	6(0-10)	6(0-10)	7(2-10)	0.43
Mood	8(0-10)	7(2-10)	7(0-10)	0.86
Walking	4(0-9)	5(0-10)	5(0-10)	0.61
Work	4(0-9)	5(0-10)	5(0-8)	0.59
Relationships	5(0-9)	6(0-10)	4(0-10)	0.19
Sleep	5(0-10)	8(0-10)	7(0-10)	0.32
Enjoyment	5(0-7)	5(0-10)	3(0-10)	0.66
Pain relief	40(0-70)	45(10-90)	30(0-80)	0.44
Pain sites are displayed using a count and percentage [x(y %)].				
Total pain sites	2(1-6)	2(1-7)	1(1-6)	0.32
Head	3(19)	4(27)	2(20)	
Chest	2(13)	6(40)	1(10)	
Abdomen	2(13)	4(27)	1(10)	
Lumbar	3(19)	4(27)	1(10)	
Ankle	5(31)	3(20)	3(30)	
Feet	6(38)	6(40)	5(50)	

Krushkal Wallis test used to calculate p value for all pain variables recorded in this table.

3.3 Pain Severity data

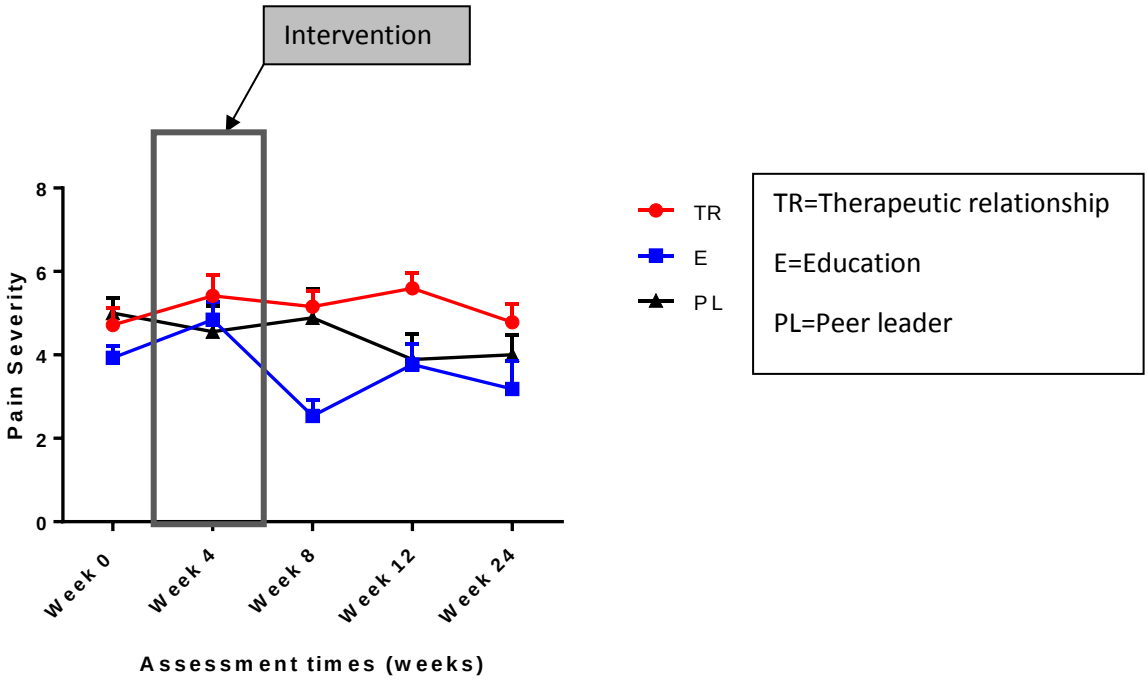

Figure 3.2 Comparison of pain severity scores

A cumulative link mixed-model ordinal regression was used to test for the effects of group, time, and group and time on pain severity. Each model was compared with a null model. There was no difference over time, however, a significant difference ($p<0.05$) was found for the scores of pain severity between the therapeutic relationship and education groups. This significance survived testing for multiple comparisons using the Holm Bonferroni test ($p>0.05$).

Therefore, the results show that there was a difference in pain severity between the therapeutic relationship and education groups at week 8 and this was maintained at week 24.

3.4 Pain Interference Data

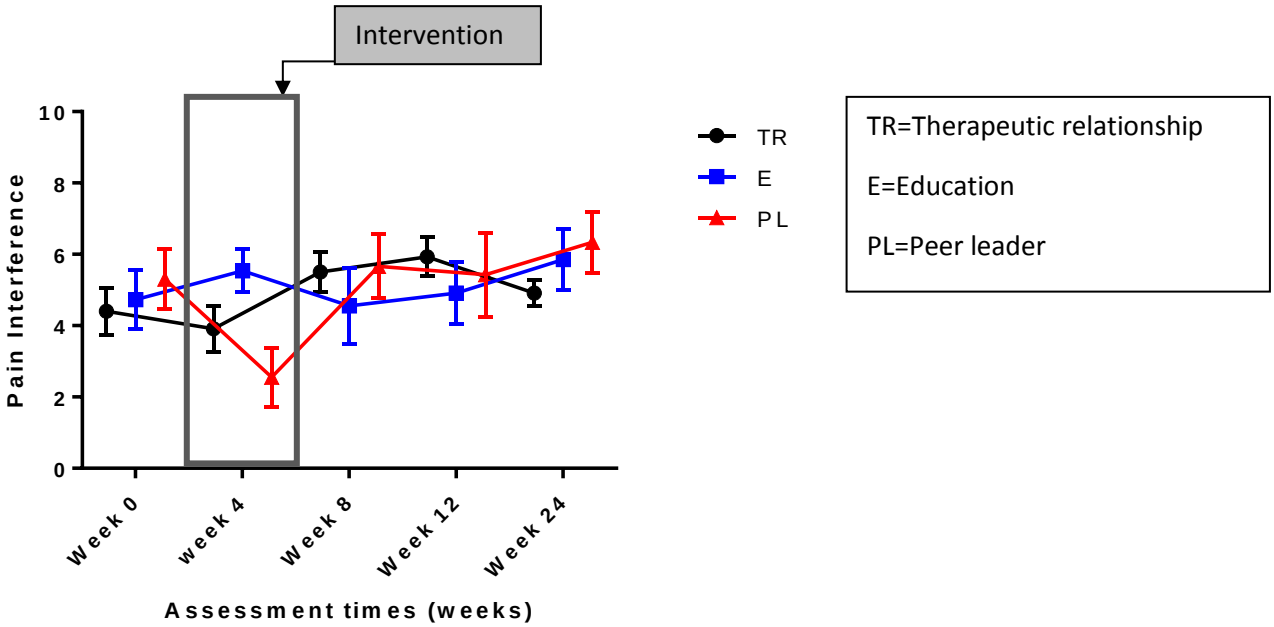

Figure 3.3 Comparison of Pain Interference scores

A cumulative link mixed-model ordinal regression was also used to compare the effects of group, time, and group and time on pain interference. Each model was compared to a null model. The effect of group, and group and time was not significant. There was an effect of time on pain interference scores ($p<0.05$) but this did not survive testing for multiple comparisons using the Holm Bonferroni test ($p>0.05$).

Therefore, the results show that across all three interventions no significant difference was found for pain interference between groups or over time.

3.5 Depressive symptoms

The data from the three intervention groups for depressive symptoms were tested for normality and found to be slightly skewed. The data were transformed using a square root transform which helped normalise the data (Appendix O).

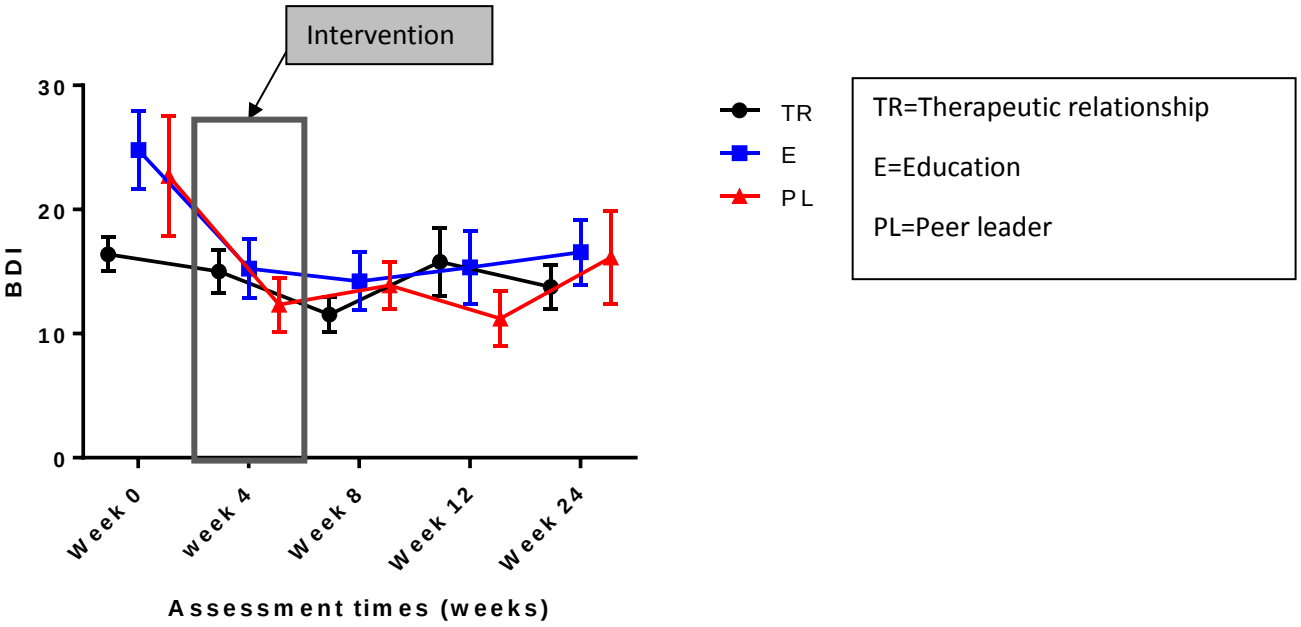

Figure 3.4 Comparison of depressive symptoms

Following the transformation of the data, a linear mixed-model regression was used to test for the effects of time, group, and time and group on BDI scores. The initial analysis showed a significant difference ($p<0.05$) over time which did not survive the multiple comparisons test using the Holm Bonferroni test ($p>0.05$). The time and group and time models were no better than the null model.

Therefore, the results show that across all interventions no significant difference was found for depressive symptoms between groups or over time.

3.6 Health Related Quality of Life Data

The data from the three intervention groups for EQ5D VAS was tested for normality and found to be slightly skewed. As the data were not normal they were analyzed using a general additive mixed-model (GAMM) with inflated beta distribution (Appendix O).

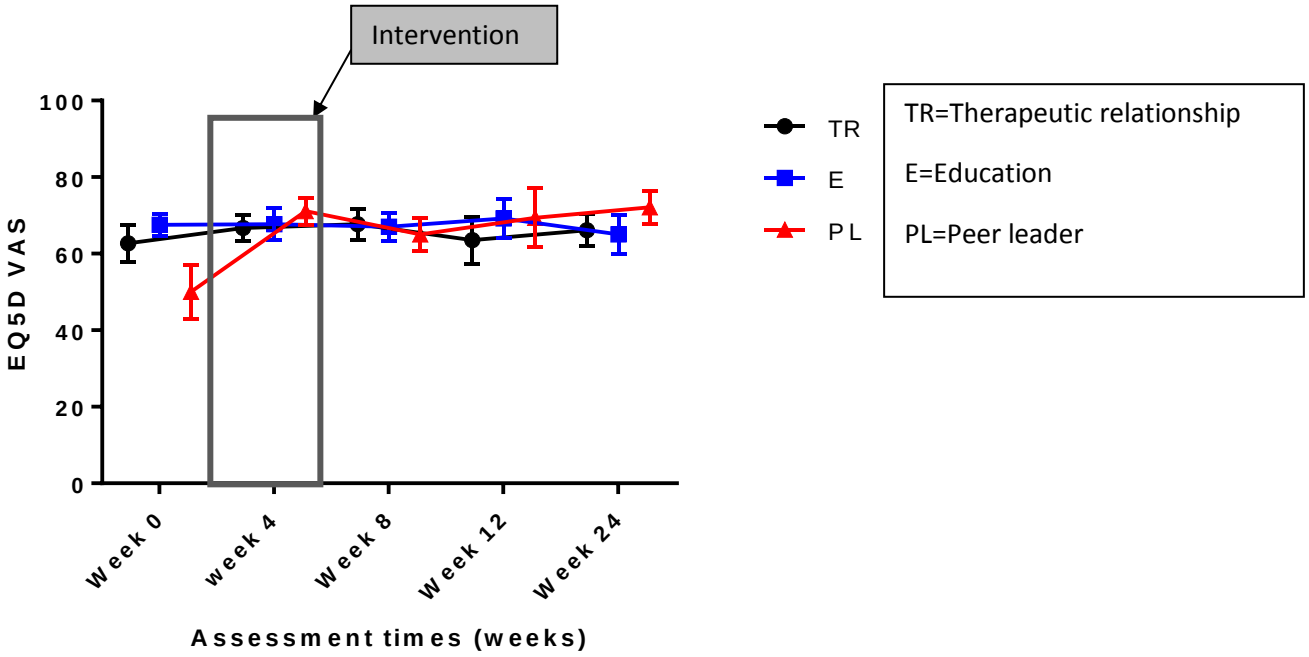

Figure 3.5 Comparison of health related quality of life

A Likelihood ratio test was performed. There was an effect of group and time on EQ5D VAS scores ($p<0.05$), however, this did not survive the multiple comparisons test using the Holm Bonferroni test ($p>0.05$).

Therefore, the results show that across all three interventions and over time there were no significant differences in health related quality of life.

3.7 Self-efficacy

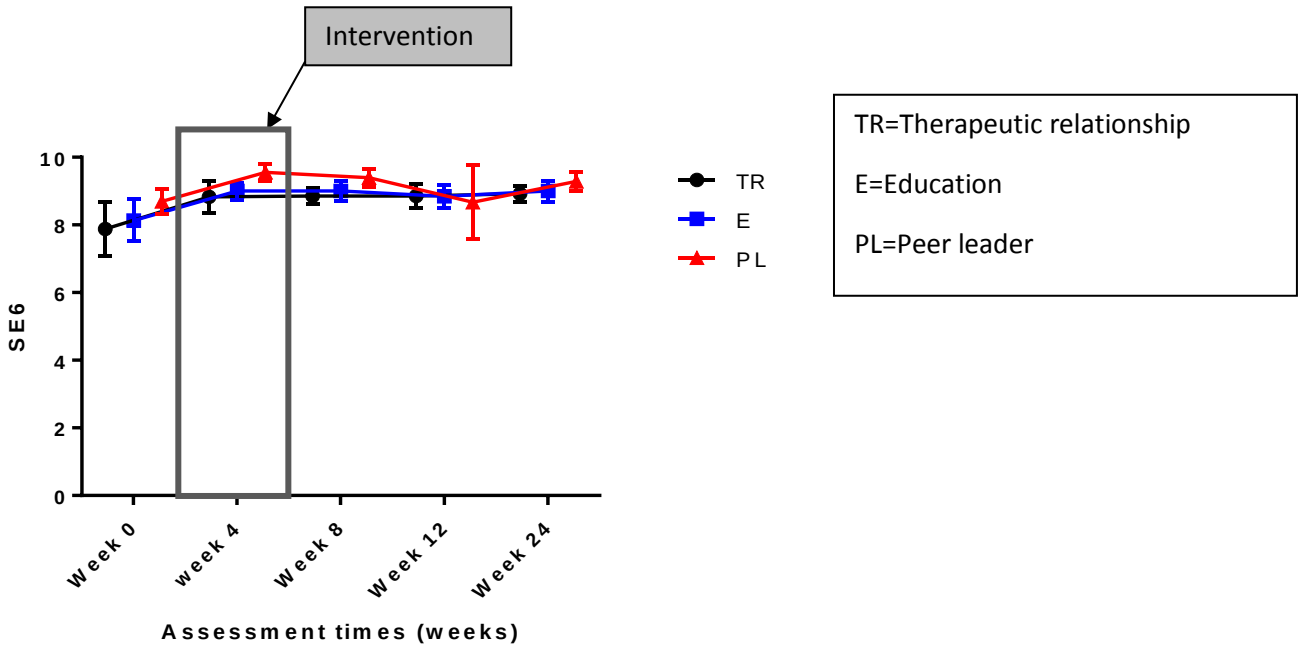

Figure 3.6 Comparison of self-efficacy

The data from the three intervention groups for the SE-6 scores was not distributed normally and attempts to transform the data were unsuccessful.

Therefore, a Kruskal Wallis test was performed to establish group differences and no significance was found between groups ($p>0.05$). A Friedman test was performed to establish significance over time and no significance was found ($p>0.05$).

Therefore, the results show that across all three interventions and over time there were no significant differences in self-efficacy. The clustering of scores near the top end of the scale suggests a ceiling effect.

3.8 Data from the Simmonds Battery of Physical tests

The data from the three intervention groups for all subtests of the Simmonds battery were compared across group and over time. The p values were calculated and two subtests were found to be not significant when compared to baseline, however, six subtests outlined below were found to be significant.

3.8.1 Preferred Walking Speed Subtest

The data from the three intervention groups for preferred walking speed was tested for normality and found to be slightly skewed. The data were transformed using a square root transform which helped to normalise the distribution of data (Appendix O)

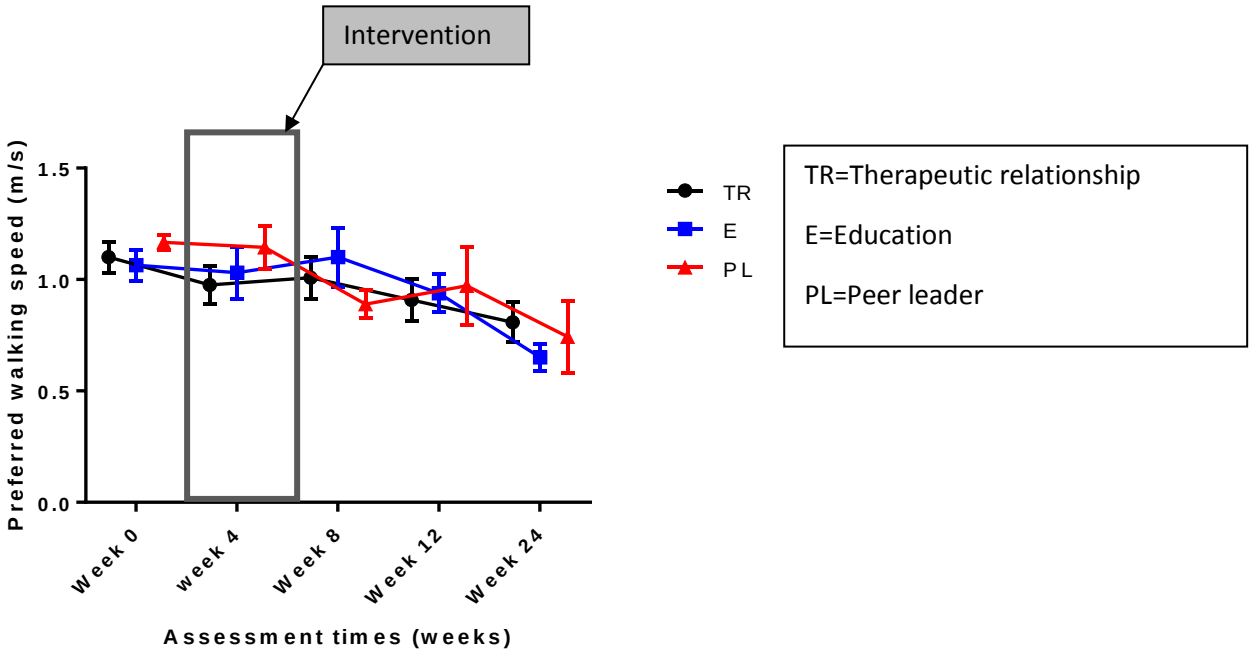

Figure 3.7 Comparison of preferred walking speed

A linear mixed-model regression was used to compare the effects of time, group and group and time on preferred walking speed. There was a significant effect of both time and group and time ($p < 0.05$) on preferred walking speed. These associations survived the multiple comparison test using the Holm Bonferroni test ($p<0.05$). The models were assessed to see which was best. There was no significant difference between the models so the simplest model was used, which identified the effect of time to be most important. Therefore, the results show that there was a significant time effect, independent of intervention group, for preferred walking speed. The preferred speed of walking decreased from week 0 to week 24 across all groups.

3.8.2 Fastest Walking Speed Subtest

The fast walking speed data was examined for normality and found to be skewed. This was not significant and no further adjustment of data were undertaken (Appendix O).

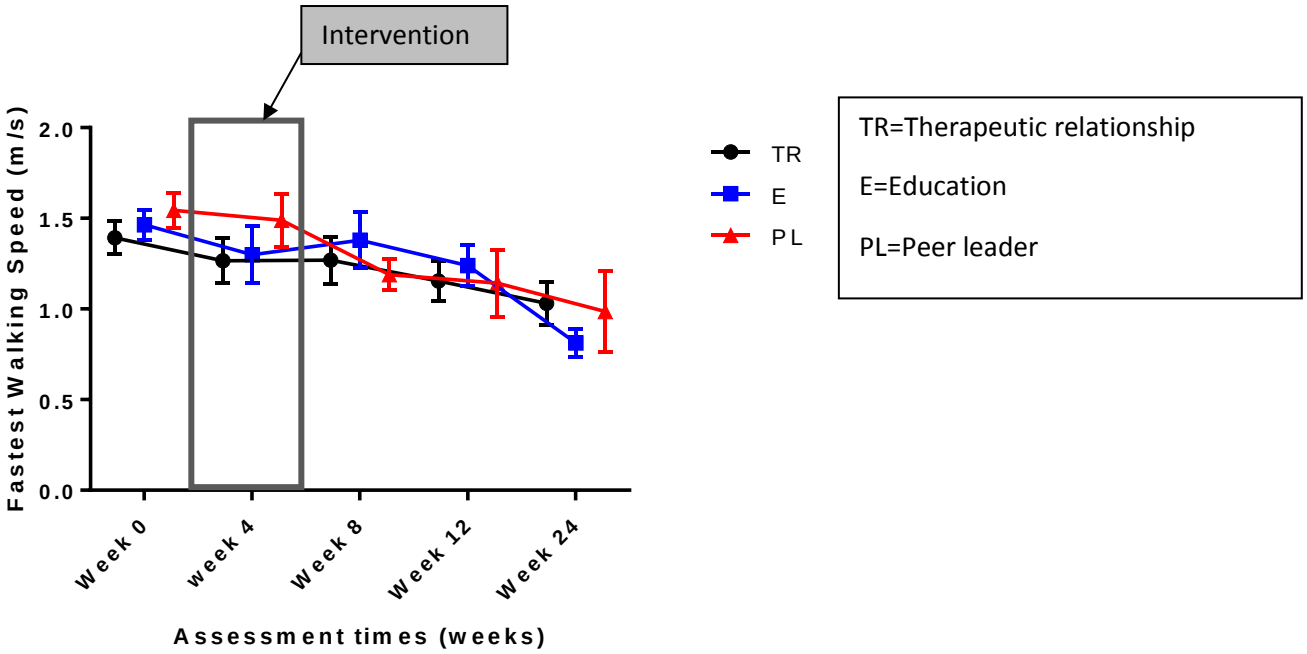

Figure 3.3 Comparison of fastest walking speed

The initial linear mixed-model regression showed a significant difference ($p<0.001$) over time which survived the multiple comparisons test.

There was a significant effect of both time and group and time on fastest walking speed ($p<0.001$). These associations survived the multiple comparison test using the Holm Bonferroni test ($p<0.05$). The models were assessed to see which was best. There was no significant difference between the models so the simplest model was used, which identified the effect of time to be most important. The fastest speed of walking decreased over time, independent of which group participants were in.

I compared the subjective data from the BPI reported by participants on walking interference using a student t test and found that there was no significant difference between week 0 and 24 for walking interference i.e. the walking interference did not get worse over time. This did not correlate with the objective data above from the preferred walking and fast walking speed subtests.

3.8.3 Distance walked in six minutes subtest

The distance walked in 6 minutes data were examined for normality and found to be slightly skewed, this was not significant and no further transformation of data were undertaken (Appendix O).

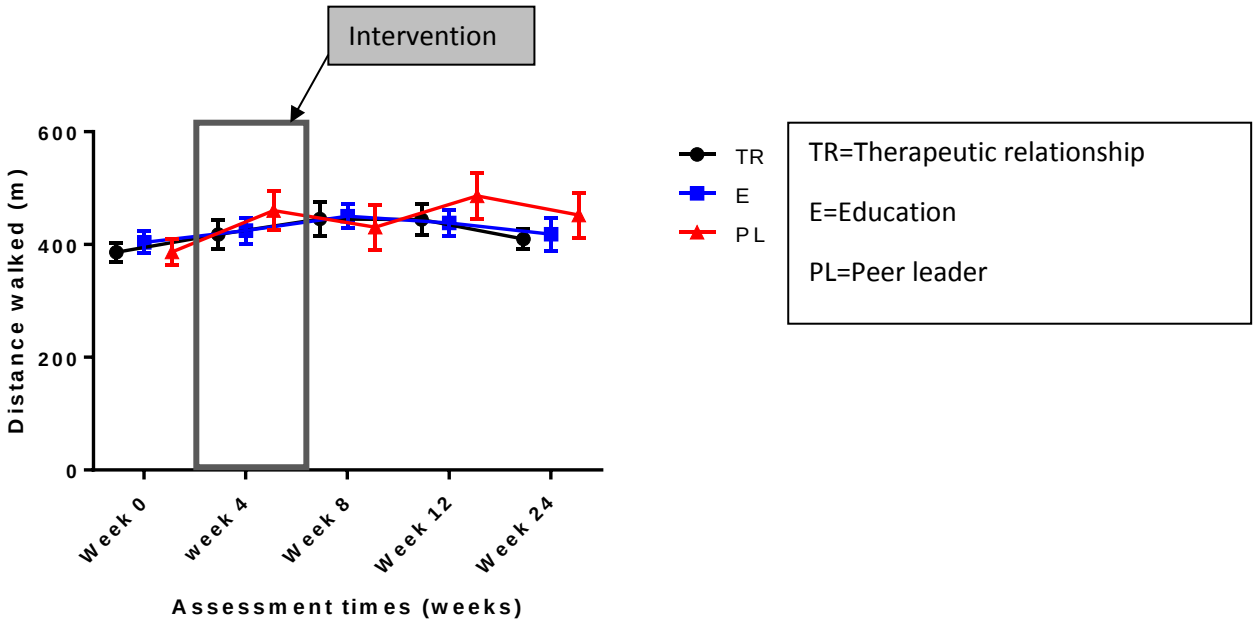

Figure 3.9 Comparison of distance walked in 6 min

Using linear mixed model regression the effects of time, group and group and time were assessed no significant effects were found ($p>0.05$).

The results therefore show that across all three interventions no significant difference was found for distance walked in six minutes at weeks 0, 4, 8, 12 and 24 between groups and over time.

3.8.4 Unloaded Reach subtest

The unloaded reach test data was examined for normality and found to be skewed. A log transformation was used to normalize the data (Appendix O). Following transformation, linear mixed model regression showed that there was a significant effect of both time and group and time ($p< 0.001$) on the unloaded reach scores. These associations survived the multiple comparison test using the Holm Bonferroni test ($p<0.001$). The models were assessed to see which was best. There was no significant difference between the models so

the simplest model was used, which identified the effect of time to be most important. Therefore, the results show that there was a significant time effect ($p<0.001$), independent of intervention group, for unloaded reach. The unloaded reach increased from week 0 to week 24 across all groups.

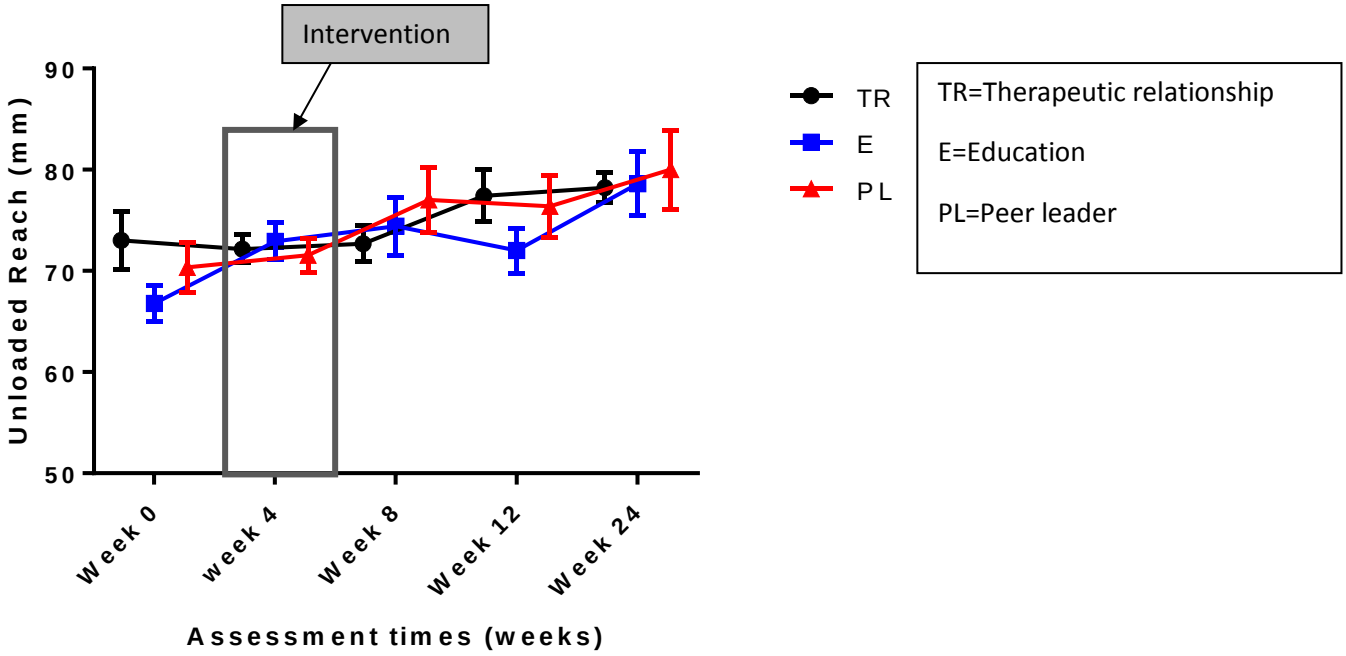

Figure 3.10 Comparison of unloaded reach test

3.8.5 Loaded Reach subtest

The data for the loaded reach test were fairly normally distributed. A log transformation was used so that the data matched the data from the unloaded reach test (Appendix O).

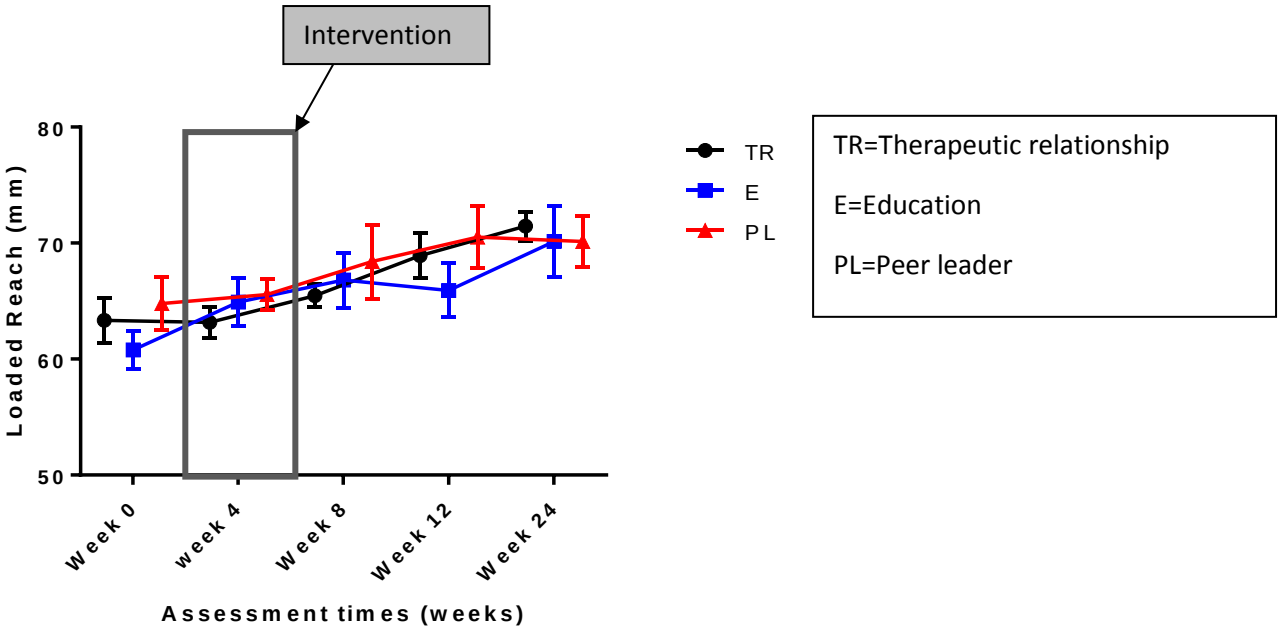

Figure 3.11 Comparison of loaded reach test

Following transformation, linear mixed model regression showed there was a significant effect of both time and group and time ($p< 0.001$) on the loaded reach scores. These associations survived the multiple comparison test using the Holm Bonferroni test ($p<0.001$). The models were assessed to see which was best. There was no significant difference between the models so the simplest model was used, which identified the effect of time to be most important. Therefore, the results show that there was a significant time effect ($p<0.001$), independent of intervention group, for loaded reach. The loaded reach increased from week 0 to week 24 across all groups.

Linear mixed model regression showed a significant difference ($p<0.001$) over time which survived the multiple comparisons test using the Holm Bonferroni test.

There were significant differences for the loaded reach test over time which indicated that the participants reached further over time from week 0 to week 24.

3.8.6 Reach Up Subtest

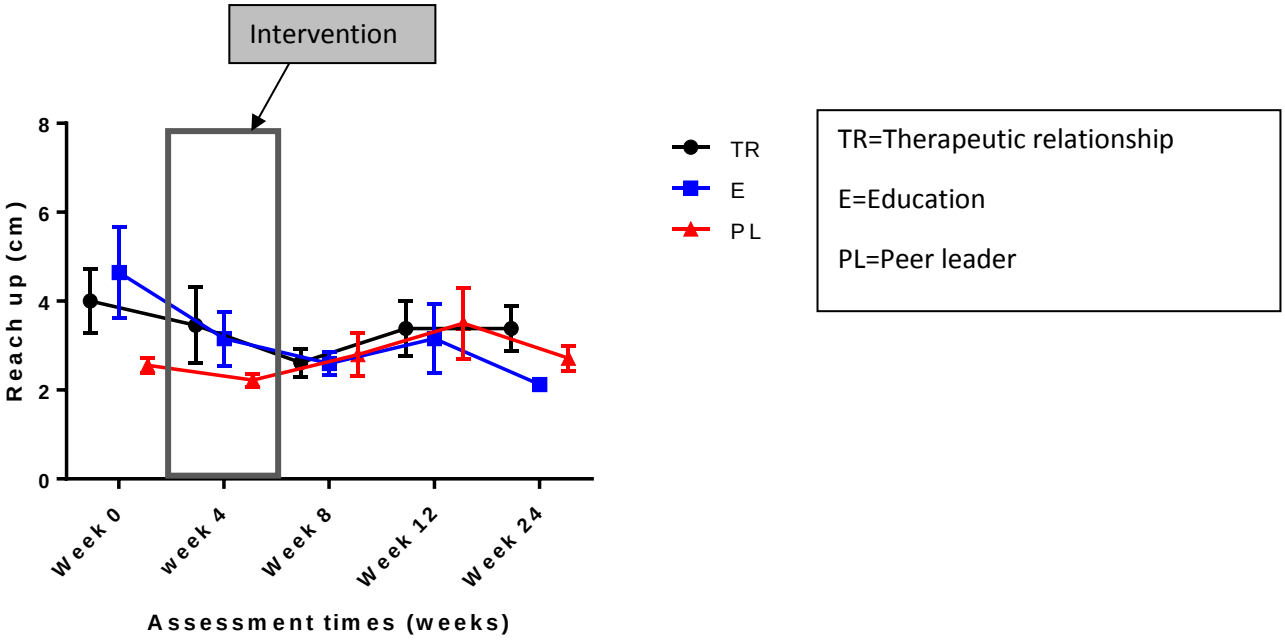

Figure 3.12 Comparison of reach up test

The data from the three intervention groups for the reach up test was not distributed normally and attempts to transform the data were unsuccessful.

A Kruskal Wallis test was performed to establish group differences and no significance was found between groups ($p>0.05$). A Friedman test was performed to establish significance over time and no significance was found ($p>0.05$).

The results therefore show that across all three interventions there was no significant difference was found over time for the reach up test from week 0 to 24.

3.8.7 Sit to stand subtest

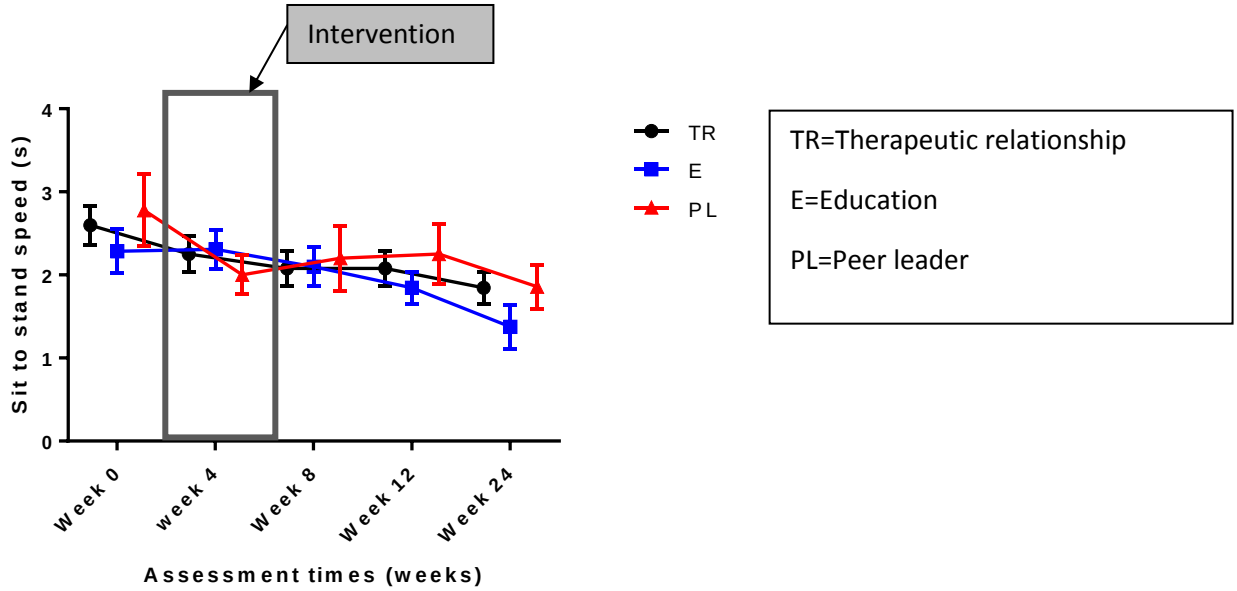

Figure 3.13 Comparison of sit to stand test

The data from the three intervention groups for the sit to stand test was not distributed normally and attempts to transform the data were unsuccessful.

A Kruskal Wallis test was performed to establish group differences and no significance was found between groups ($p>0.05$). A Friedman test was performed to establish significance over time and a significance was found ($p>0.001$).

This significance did survive the multiple comparisons test ($p>0.001$) using the Dunn's test.

The results therefore show that across all three interventions there was a significant difference over time for the sit to stand test from week 0 to 24. The participants performed this test faster as shown in the graph above.

3.8.8 Belt tie Subtest

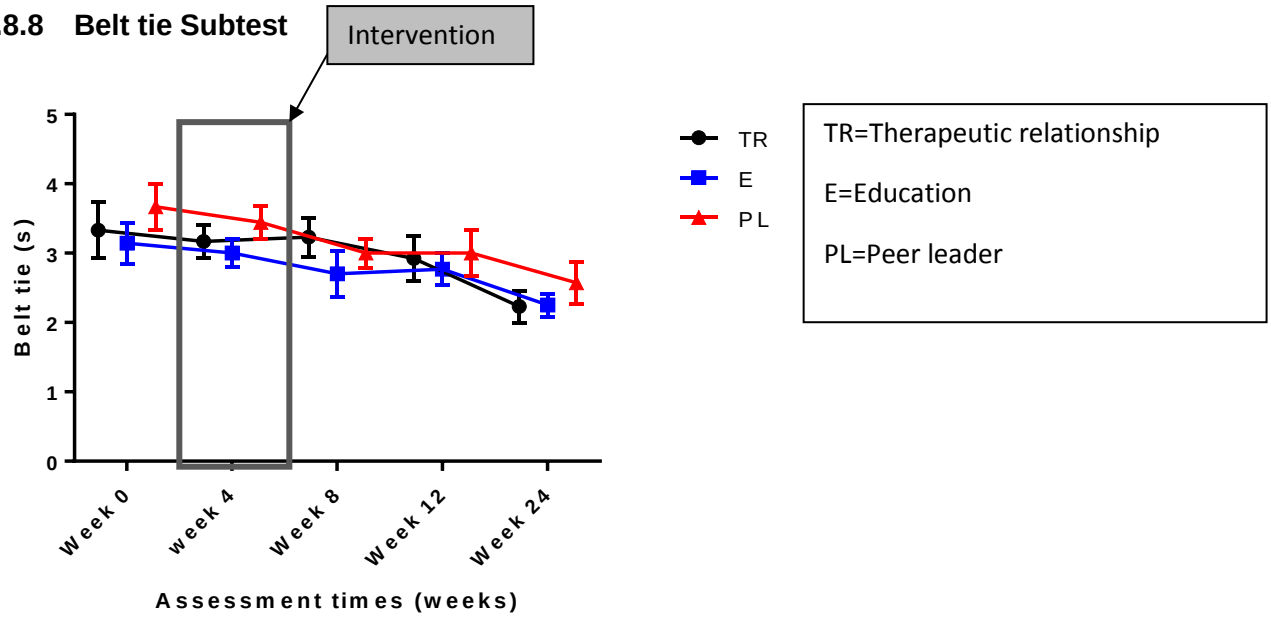

Figure 3.14 Comparison of belt tie test

The data from the three intervention groups for the belt tie test was not distributed normally and attempts to transform the data were unsuccessful.

A Kruskal Wallis test was performed to establish group differences and no significance was found between groups ($p>0.05$). A Friedman test was performed to establish significance over time and a significance was found ($p>0.001$). This significance did survive the multiple comparisons test ($p>0.001$) using the Dunn's test.

The results therefore show that across all three interventions there was a significant difference over time for the belt tie test from week 0 to 24. The participants performed this test faster as shown in the graph above.

3.9 Feedback from group participants

In addition to the quantitative data collected, participants who attended the peer led groups were given an opportunity to fill in questionnaires evaluating the group. This questionnaire is attached in Appendix N. Themes were identified and displayed in Table 3.3.

Table 3.7 Comments from feedback questionnaire

Question: What did you like about the course?
Participant 36: “I liked everything about the course especially about how to manage my health, stress etc. I really liked this book” Participant 35: “ It also taught us to manage our chronic illness” Participant 22 ”And how to deal with things that I face at home and in my life” Participant 53 ”Everything because it taught me about managing myself something’s I didn’t know and things that I was not keen to ask my doctor and specially to know my medication” Participant 51: ”I just like everything about the course, I learn how to manage myself” Participant 57: “I got many things how I must keep myself, health and to teach other people”
Participant 35: “ I like that it was education, the ideas that we got from others, we were able to talk about challenges that meet on the way” Participant 22: “ It make me meet new people, how to work as a group” Participant 4: “I liked the ideas we get there and the people that we met they were friendly” Participant 40: “ It make me feel better than before , I like to share things with other people”
Question: What did you like about the work book?
Participant 11: “It took me to a different level, it made me understand that this disease can be managed” Participant 35: “Everything about it and it makes me alert of things that I should do in the future” Participant 22: “It keeps me going and makes me know how to plan or do things. I can keep it and use it anytime when I want to” Participant 4: “ It was very smart I learnt everything, that I can manage myself to the symptoms I get each and every time and my disease” Participant 51: “To manage my life, I just learned how to manage my life”
Participant 36: “I liked the fact that it had everything I needed exercises etc.” Participant 57: “ This book gives me more information about people who get HIV, it contains good information about HIV and how to stop pains if you got”
Participant 53: “It showed me that I can learn more and become an ambassador for HIV and teach schools, churches and underprivileged people”

In response to the question *“What didn’t you like about the course?”* all participants answered nothing and gave feedback that the course was too short.

In response to the question *" Was there anything more you would like to learn that wasn't in the course?"* the participants answered that everything was covered and that they did not feel anything else was needed.

In response to the question" *What didn't you like about the workbook?"* Most participants answered nothing, with one participant indicating that the book should include more information.

In response to the question*" Is there anything you would like to add or change in the workbook?"* Most participants answered "no" with one participant requesting information on safe sex and family planning and another asking for more information on HIV/AIDS.

3.10 Conclusion

In conclusion the study found significant differences for the pain severity scores between the therapeutic relationship group and education group. Significant differences were also found for the loaded reach, unloaded reach, sit to stand, belt tie, preferred walking speed and fastest walking speed subtests of the Simmonds battery. The loaded and unloaded reach, sit to stand and belt tie scores improved, while the preferred and fastest walking speed test scores reduced. These differences are all outlined above with graphs and summaries of the p values found. There were no significant differences found for pain interference, depressive symptoms, health related quality of life, self-efficacy or any of the other subtests on the Simmonds battery.

In addition the comments obtained from the peer leader group participants show that all participants found the group and information manual beneficial.

Chapter 4 Discussion and Conclusion

4.1 Introduction

In this study I set out to examine whether three non-pharmacological interventions would be effective in managing chronic pain in PLWHA and if so, which was the most effective. These three interventions were:

- the use of a therapeutic relationship alone,
- the use of a therapeutic relationship with an educational resource or
- the use of a therapeutic relationship with a peer led self-management intervention plus the educational resource.

The primary outcome was pain severity and the secondary outcomes were pain interference, self-efficacy, and health related quality of life, depressive symptoms and physical function. The results showed significant differences for the pain severity scores between the therapeutic relationship group and education group. Significant differences were also found for the loaded reach, unloaded reach, sit to stand, belt tie, preferred walking speed and fastest walking speed subtests of the Simmonds battery. The loaded and unloaded reach, sit to stand and belt tie scores improved, while the preferred and fastest walking speed test scores reduced.

It is important to note that the high attrition rate of 58% resulted in the study being underpowered and this possibly contributed to the lack of significance found in the results. Thus all results reported must be seen in this light and any significant results reported cannot be construed as substantial findings due to this limitation. This limitation is discussed in further detail later in this chapter.

South Africa has the largest population of PLWHA in Sub Saharan Africa (UNAIDS, UNAIDS fact sheet 2015). Consequently management of HIV and all related symptoms and co-morbidities has become a priority for the South African Department of Health (UNAIDS, UNAIDS South Africa 2013, Department of Health 2014). Pain is commonly experienced by PLWHA around the world and is prevalent in the South African HIV/AIDS population (Norval D A, 2004; Harding et al. 2011; Bhengu et al. 2011; Farrant et al. 2012; Peltzer K, 2013). It has been shown that function; quality of life and productivity are affected in PLHWA who suffer from pain (Hughes et al. 2004; Astoro et al. 2007; Van As et al 2009; Balderson et al. 2013; Merlin et al. 2013; Galantino et al. 2014).

Management of chronic pain in PLWHA has been mostly through pharmacological interventions which have been found to be ineffective or illegal in the case of cannabis (Finnerup et al. 2015; Kamerman and Mitchell 2011; Parker,Stein and Jelsma, 2014; Degenhardt et al. 2015; Dinat et al. 2015). This approach also does not follow the biopsychosocial approach usually recommended in the management of chronic pain (Marcus et al. 2000; Siddall and Cousins 2004; Cheatle M D 2016) and leaves a gap in research with respect to the use of non-pharmacological management in this population. Non-pharmacological management has been shown to improve pain intensity and interference (Evans et al. 2003; Trafton et al. 2012) health related quality of life (Mkandla, Myezwa and Musenge, 2016) , anxiety, energy and sleep (Henrickson M, 2001; Mulkins et al. 2014) as well as reduce symptoms (Gifford et al. 1998, Webel A R 2010). However, not all of these studies are in PLWHA who suffer from chronic pain. There is a paucity of research on non-pharmacological interventions in the HIV population globally and in South Africa.

The current study was based on a previous study using the Positive Living self-management programme (Parker, Jelsma and Stein 2016[a]) with the addition of a participant group that included therapeutic relationship alone as an intervention. This was done to establish if the therapeutic relationship played any part in the positive outcomes generated in the previous study, as positive results were reported for both the education alone and peer led groups by the previous study (Parker, Jelsma and Stein 2016[a]).

Pain severity

The study results showed there were no significant differences for pain interference, depressive symptoms, self-efficacy and health related quality of life. The earlier results of (Parker, Jelsma and Stein, 2016[a]) had shown a reduction in pain severity and interference as well as an improvement in self-efficacy, health related quality of life and depressive symptoms for all participants.

Average pain severity was not included in my calculation of the pain severity score. A previous validation study of the BPI (Mpahlehle, Mitchell and Kamerman, 2008) showed that ‘average’ pain intensity did not translate well in isiZulu and that the term average pain translated to ”medium”, “pain in between” or “mild” pain (Mpahlehle, Mitchell and Kamerman, 2008). Thus the average pain severity reported by amaZulu participants would not be an accurate reflection of their average pain (where average is the patients rating of pain that is felt for most of the time) and this would impact on the validity of the pain severity score making it an unreliable measure. In my study I therefore excluded average pain intensity

when calculating the pain severity score to ensure a more reliable measure of pain severity. The participants in my study had a mild to moderate level of pain severity as shown graphically in figure 3.2 in the results chapter. Although there was a significant difference between the education and therapeutic relationship group over time this may not be clinically significant. The reason for this could be that the education group experienced significant attrition at week 8 and 24 with the largest overall number of loss to follow up coming from this group. This may imply that those participants who did not return for follow up may have been the individuals with a higher pain severity. The remaining group participants who returned for follow up may have had a reduced pain severity. The pain severity scores would thus be biased towards a lower level of pain severity as a result. These findings are unusual and there is no good reason that the researcher is aware of that could have been responsible for these results. This could be attributed to an erroneous finding in the study results.

The study by Parker Parker, Jelsma and Stein (2016[a]) as well as the current study showed no differences between the intervention groups for self-efficacy, pain interference and health related quality of life when the intervention groups were compared with the exception of pain severity mentioned above. The differences found in the previous study (Parker, Jelsma and Stein, 2016[a]) and the current study over time were independent of the group allocation of participants with the exception of pain severity as discussed. The peer led self-management group has shown some efficacy in other chronic conditions including HIV and chronic pain (Gifford et al. 1998, Lorig et al. 2001; Gitlin et al. 2008, Kravitz et al. 2011), however, these results have not been replicated in randomized controlled trials and therefore may be questioned. The results from Parker, Jelsma and Stein's 2016[a] study and the current study demonstrate that peer led self-management groups as a non-pharmacological management choice in this population requires further investigation.

Self-efficacy and empowerment

When the study results were compared for self- efficacy, the current study had a mean of nine out of ten at weeks 0 and 24. In the previous study by Parker, Jelsma and Stein (2016) [a]the mean at baseline was calculated at 7.09(SD1.58) at week 0 and 8.07(SD1.43) at week 24 which was found to be statistically different (p=0.04). The self-efficacy scores from the current study demonstrated a possible ceiling effect when the data were analysed i.e. the scores were high at baseline so could not have been significantly improved upon. Ninety seven percent of participant's scores at week 0 demonstrated a high level of self-efficacy which remained the case at week 24 for all participants in this study. This meant a clustering

of scores near the top end of the scale. The participants in Parker, Jelsma and Stein's (2016[a]) study seemed to have a lower level of self-efficacy at week 0 and the scores were not clustering at the top end of the scale, thus the ceiling effect did not occur. Gifford (1998) also reported high levels of self-efficacy but did not seem to demonstrate a ceiling effect either. A cross sectional study that compared pain and depressive symptoms in spinal cord injury patients found that higher self-efficacy was linked to lower pain interference and less severe depressive symptoms (Pang et al.2009). The mean in this cohort (Pang et al.2009) was 6.5(SD1.6) which was significantly lower than the mean found in my study. It is possible that the higher level of self-efficacy found in my cohort is the reason that no other significant changes occurred. This could mean that my study population was quite empowered already which is possibly why this intervention did not really work with them. It could mean that these self-management interventions only work in people who have lower levels of self-efficacy who are thus more disempowered. Gifford (1998) also reported that their cohort was very empowered to begin with.

Simmonds Battery Results

Significant differences were found over time in my study for all participants for six components of the Simmonds battery.

There was a significant reduction in preferred and fastest walking speeds over time between weeks 0 and 24 in the study groups. Due to logistical reasons these tests were carried out in a hospital corridor (the other tests were carried out in a private room) where passersby would occasionally stop to observe the test and ask the research assistants questions about the test. It is possible that the research participants would have felt more anxious about performing this test in a public space initially until they got used to the procedure and being observed by other people not involved in the study. Thus results could also be attributed to a decrease in anxiety at being tested, participants would have become more comfortable with research participants and the test procedure which may have led to a decrease in speed as they may have felt more relaxed. Like the findings on pain severity these findings are unusual and there is no other reason that the researcher is aware of (other than the one cited above) that could have been responsible for these results. This could be attributed to an erroneous finding.

I compared the subjective data from the BPI reported by participants on walking interference using a student t test and found that there was no significant difference between week 0 and 24 for walking interference. This infers that the participants did not feel that they were worse in terms of their walking but objectively reduced their walking speeds. Previous studies in

cohorts with pain such as total knee arthroplasty, lumbar spinal stenosis and ankylosing spondylosis have shown that participant's subjective and objective data do not always correlate (Bolink, Grimm and Heyligers 2015; Tomkins-Lane et al. 2012; Van Weely et al. 2012). This could be due to the fact that self-report measures do not measure the same specific aspects of physical function (Bolink, Grimm and Heyligers 2015; Van Weely et al. 2012) as an objective physical test. This may be the case for the preferred and fastest walking speed data in this study as it does not correlate with the self-reported walking interference scores from the BPI. There may also be a risk of self-report bias from the study participants which could explain these results.

There were significant differences for the loaded reach test and the unloaded reach test values over time. The participants reached further on the loaded reach test by week 24 than they did at week 0. In addition all participants performed the sit to stand and belt tie tests faster by week 24. This could be due to improved physical function or the participants reaching further, sitting faster and tying the belt faster after having many opportunities to practice the tasks. This could also be attributed to the effect of mere participation in the research study. It has been demonstrated previously that participation in a research study or overt evaluation during a research study may influence the outcomes or study results (Cizza et al.2014; Wolfe and Micahaud, 2010; Robles-Garcia et al. 2015, Gazzi Macedo et al. 2012) and may result in an overestimation of functional improvement (Wolfe and Micahaud, 2010). These findings are unusual and could be an erroneous finding. Clinically this may mean what an individual reports on physical function may not be an accurate representation of their actual physical function thus it is important to use more than just self-report outcome measures for assessment in clinical practice in order to get a more accurate picture of an individual's function. This would specifically apply to an individual who suffers from a chronic condition such as HIV as their own perception of their illness and symptoms may influence their self-report. The recent IMMPACT recommendations regarding the assessment of physical function recommend that self-report of function be combined with an objective physical function test which supports the above premise. In addition the authors note that physical function performance tests do not always reflect the everyday function that an individual engages in within their activities of daily living and may therefore not reflect their actual capacity (Taylor et al. 2016). This may also be true in my study and may be the reason the self-report conflicts with the actual physical performance of walking as the participants may be relating the interference question on the BPI to the distance they are required to walk on a daily basis which may include steps for example.

The role of the therapeutic relationship

Parker, Jelsma and Stein's (2016 [a)] participants were less empowered than my cohort due to the lower self-efficacy scores, however, they may have established a better therapeutic relationship with the research assistant, which then resulted in a positive effect from the peer led self-management programme and educational material provided. It is possible that the intervention worked better in her cohort due to this. My study used two research assistants thus the participants did not always see the same research assistant on follow up visits which may have hindered the development of a therapeutic relationship. My study sought to find out if the therapeutic relationship had the same effect as educational material or the self-management programme. The previous study was not able to specifically report that the results seen could be attributed to the therapeutic relationship alone or the interventions supplied (Parker, Jelsma and Stein 2016[a]). Unfortunately the use of two research assistants may have resulted in interference in the development of a good therapeutic relationship which could account for the lack of changes seen over time in my study.

Group differences and the inclusion of male participants

The cohorts for Parker, Jelsma and Stein's (2016[a])'s study and my study did have some significant differences. The previous study included only Xhosa speaking, urban female participants while the current study included both urban male (n=12) and female (n=29) participants from various language backgrounds. Although the number of male participants was low, the addition of male participants may have influenced the study outcomes as male participants have been shown to report less pain (Deeny et al. 2015, Munce and Stewart, 2007). Thus the changes in pain severity and interference may have been less marked in my study due to the inclusion of male participants. During recruitment the research assistants reported that the male participants would not report pain in a public space such as the clinic waiting queue but would later report significant pain in a one on one interaction away from other people. This could explain the higher number of female participants recruited. Men are also reported to feel stigmatized by being seen as sick (Treves-Kagan et al. 2016) which may have contributed to the lower recruitment of men. This may mean that management of HIV related pain in men may be under recognized and subsequently under treated due to the lack of reporting by these men. In addition more male participants did not attend the first session of the self-management group and there was a higher dropout rate from the male group when compared to the female group. Those that did attend the group for the full duration participated just as enthusiastically as the female participants.

The participants in my study were mostly unemployed (59%, 24/41) and the majority had secondary school education (n=37) which was similar to the previous study (Parker, Jelsma and Stein 2016[a]). The majority of participants were in a relationship (59%, 24/41) with 3 married and 14 single participants which included those divorced or widowed, while the study by Parker, Jelsma and Stein 2016 [a]had a majority of single participants. This could possibly mean that those participating in the Parker, Jelsma and Stein (2016 [a]) study were less empowered than my study participants due to being more lonely and vulnerable. My participants had more support systems due to being in relationships.

Evaluation of the education manual and positive living programme

The peer leader group in my study completed questionnaires regarding the Positive Living programme and the education manual they were given. The comments were positive and themes of self-management, interaction with others, motivation and self-confidence, empowerment and information were identified. All participants felt the manual and programme helpful. However, reporting of these comments may be biased as the education group were also given the Positive living manual but were not asked to comment on the manual, thus the comments may not be an accurate reflection of the manual itself and may have been influenced by group participation. The participants did not objectively improve on the outcome measures that were self-report questionnaires but had all enjoyed the self-management group and found it useful. It may be that the positive effects of participation in the group were short lived and did not last until the 24 week follow up when the final assessment of outcomes were done. Webel (2010) had similar results with the study participants reporting that they found the group beneficial but this did not translate into significant changes on the outcome measures.

The results of (Parker, Jelsma and Stein, 2016a) had shown a reduction in pain severity and interference as well as an improvement in self-efficacy, health related quality of life and depressive symptoms for all participants. In comparison the current study did not have the same results thus no conclusions can be drawn at this stage about the role of a therapeutic relationship or the effects of the other interventions used in this study. Thus I believe that a change in current clinical practice is not warranted.

Limitations

The lack of efficacy in this study could be attributed to the small sample size. Although the possibility of drop outs was factored in to the initial power calculation with a possible dropout rate of 16%, the actual dropout rate was larger than expected at 58%. This was attributed to

various reasons such as loss of contact, moving to another city, ill health, obtaining employment and not arriving at the first session of the peer led self-management group. Possible reasons for non-attendance of the first group session were transport availability or a lack of understanding as to what the group participation entailed. Participation in the self-management group required regular weekly attendance which may have been logistically difficult for some participants even though the transport costs were reimbursed. This resulted in an eventual 28 participants in total which was far lower than the anticipated 20 participants per group used for the sample size calculation. The study was thus likely underpowered and this possibly contributed to the lack of significance found in the results.

It was found that participants who did come back for follow up were not consistent with attendance i.e. often missing appointments or follow ups and returning for the next appointment. This could be due to the fact that there were five time points at which the assessments were done and that the participants found it logistically difficult to return so often for follow ups. The attendance was therefore inconsistent.

Several attempts were made to counteract the loss to follow up. Participants were sent reminder sms's for appointments and called when they did not arrive on the day. In addition they were called afterward to allocate a second appointment date and time and two contact numbers were taken at recruitment stage to ensure that the researcher could contact the participants. The only avenue not explored was the use of home visits when the participants did not arrive or were not contactable by numbers provided. This is an option that should be considered for future research undertaken in this setting.

There were several results that showed statistical significance initially but did not survive testing for multiple comparisons; these were pain severity and interference and depressive symptoms. It is possible that with a larger sample size these results may have remained significant with robust analysis. A longer follow up period of 12 months with follow up assessments spaced at 3 month intervals may have resulted in less sample attrition and provided data on the longevity of the study results. Another reason for the lack of significant results could be that the pain severity variable from the BPI was used in the power calculation of the sample size. The lack of significance in the other variables measured could be attributed to the fact that they were underpowered as the power analysis considered pain severity and not the other variables measured in the study.

Self-report bias may have arisen as several of the outcome measures were self-report questionnaires and the objective physical function tests did not correlate with these results as discussed previously. The physical test may also not reflect the daily activity that the

participant engages in and uses as a frame of reference when answering the questions as discussed above.

The reporting of the qualitative comments may also be biased as I did not obtain feedback from the education group who also received the positive living manual. The positive feedback received may not have been replicated by the education group as they had not received the peer led intervention.

The development of a therapeutic relationship could also not be measured so there was no way to establish if a therapeutic relationship had developed between the research assistants and the study participants. In addition the participants did not see the same research participant for all follow up appointments which may have affected the development of the relationship. This is therefore a study limitation as it is not clear how successful the generation of a therapeutic relationship was in this study.

The lack of a placebo group or intervention is a limitation of the study as the result cannot be compared to the effect of no intervention. Thus how significant the study results really are is difficult to ascertain. Placebo groups should be included in future research to ensure that results will be more robust.

4.1 Recommendations for future research

Future directions for research in management of chronic pain in PLWHA should focus on longer intervention and follow up periods to ensure longevity of any significant results obtained. Larger sample sizes need to be recruited to ensure that the sample is sufficiently powered despite any attrition that may occur. Based on the above attrition rates I would recommend a larger sample size to account for an approximate 60% attrition rate. I would also recommend home visits be included to try to keep participants in the study if they do default on follow up appointments. More studies should include the use of objective physical function data such as the Simmonds battery of physical tests so that this can be compared with self-reported physical function in this population. This is indicated by the fact that very few studies reviewed in the literature review chapter actually used physical performance tests to evaluate function.

The effects of anxiety were not researched in this study and could possibly have contributed to the decreased walking speeds, thus anxiety should be added to future studies undertaken. The hospital anxiety and depression scale (HADS) is recommended.

4.2 Conclusion

This research adds to the body of work done on non-pharmacological interventions in PLWHA and chronic pain. Although there were few significant findings, the study has demonstrated that physical function may be affected by non-pharmacological interventions. It is clear that self-reported physical function in this cohort did not match the physical function observed during the Simmonds battery of functional tests. Significant improvement over time in 4 components, indicate that the non-pharmacological interventions do indeed have a positive effect on function. It is clear from the study that self-report of physical function does not match with actual physical function scores. Clinically this is significant as healthcare providers often rely on a patient's self-report of function when evaluating their level of function. Clinical practice should always include some form of objective physical function test so that a more accurate picture of the patient's actual function is achieved.

The role that anxiety played in the study results is unclear and this would need to be added to future studies to establish the effect if any present.

In this cohort as no differences were found between the intervention groups except for pain severity, which requires further investigation as discussed above. This may mean that by using a therapeutic relationship effectively, a health care provider might have the same effect, as providing other resource intense modalities such as patient education or self-management groups. This could be a cost effective modality if all healthcare providers put more effort into creating a good therapeutic relationship with their patients which could improve patient outcomes especially in settings like the public healthcare system where patients are given limited attention due to limited resources in South Africa. If one takes the current results at face value it appears that the effect of the peer leader and education interventions when compared to the therapeutic relationship group did not have a significant impact on the variables measured. If this was not the case there would have been larger more significant differences between the groups. Therefore one can conclude that these interventions may not be as helpful as first thought when the study was initiated. Once again this theory would need to be tested in a larger cohort with a placebo arm.

Several of the significant results obtained in this study are difficult to explain such as the between group difference in pain severity with the education group scoring lower than the peer led group, the slow performance of gait in the later follow up assessments and the seemingly unrelated improvement of physical function to the intervention (therapeutic relationship). I have attempted to explain these findings above through the effects of study participation, possible anxiety during the initial study phase and the possibility of anomalies or erroneous findings. These results need to be investigated further with a larger cohort and

a placebo group to establish if pain severity does improve and if objective physical function assessment differs from subjective physical function.

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Appendix A Ethics Clearance Certificate

R14/49 Ms Dershnee Devan et al

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140877

NAME: (Principal Investigator)	Ms Dershnee Devan et al
DEPARTMENT:	School of Physiology Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	Comparison of Non-Pharmacological Interventions for Reducing Pain in Individuals with HIV
DATE CONSIDERED:	29/08/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Antonia Wadley
APPROVED BY:	Professor P Cleaton-Jones, Co-Chairperson, HREC (Medical)
DATE OF APPROVAL:	08/09/2014

This clearance certificate is valid for 6 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit the application to the Committee. I agree to submit a yearly progress report.

Principal Investigator Signature Date 8/09/2014

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B Pan African Trial registry number



SOUTH AFRICAN COCHRANE CENTRE

PO Box 19070, Tygerberg, 7505, South Africa
Francie van Zijl Drive, Parow Valley, Cape Town
Tel: +27 21 938 0838, Fax: +27 21 938 0835
Email: cochrane@mrc.ac.za

30 October 2014

To Whom It May Concern:

RE: A comparison of non-pharmacological interventions for reducing pain in individuals with HIV.

As project manager for the Pan African Clinical Trial Registry (www.pactr.org) database, it is my pleasure to inform you that your application to our registry has been accepted. Your unique identification number for the registry is **PACTR201410000902600**

Please be advised that you are responsible for updating your trial, or for informing us of changes to your trial.

Additionally, please provide us with copies of your ethical clearance letters as we must have these on file (via email, post or fax) at your earliest convenience if you have not already done so.

Please do not hesitate to contact us at +27 21 938 0835 or email epienaar@mrc.ac.za should you have any questions.

Yours faithfully,

Elizabeth D Pienaar
www.pactr.org Project Manager
+27 021 938 0835

Appendix C Sample Calculation

Sample Size Determination:

Sample size calculations were based on the mean and standard deviation (SD) scores for the Pain Severity Scores (PSS) of the BPI from the study by Parker, Jelsma and Stein (2016[a]). The mean and SD scores for all participants at baseline were 5.32 ± 1.93, and the subsequent scores during data collection were: 5.55 ± 1.65 (week 0), 3.81 2.89 (week 4), 3.1 ± 3.03 (week 8), 2.79 ± 3.38 (week 12), 1.81 ± 2.87 (week 16). Sample size calculations were therefore performed using standard deviations of 1.6, 2 and 3.

A 3 point change in the PSS on the BPI is regarded as being clinically significant. The minimum specific difference of interest was therefore set at 3 points. Data will be collected at 5 different time points in this proposed study, namely at week 0, week 4, week 8, week 12 and 6 months. The total number of data collection time points will therefore be 5.

The desired alpha level was set as 0.05 and the desired power was set at 0.9.

Power	Group Size	Time Points	Difference to be detected	Standard Deviation	Alpha Level
0.92831	4	5	3	1.6	0.05
0.91836	6	5	3	2	0.05
0.90848	13	5	3	3	0.05

The above shows that for a conservative estimate of the SD being 3, a group size of 13 participants per group is needed. This translates to 39 participants in total. However, due to a number of identified cultural factors relating to gender, two separate groups (one female and one male) for the experimental group is required. In order for groups to be effective in achieving a change in behaviour, they should be between 8 and 12 people in size. Therefore, in order to have functional peer-groups and to accommodate for drop out it was decided that a total number of 10 participants per gender group would be appropriate. This translates to a total of 20 participants per group. The total sample size would therefore need to be 60 participants.

Revised sample size calculations for groups of 20 would therefore result in power estimates of 100% for a SD of 1.6, 99.99% for SD of 2 and 98% for SD of 3.

Power	Group Size	Time Points	Difference to be detected	Standard Deviation	Alpha Level
1.00000	20	5	3	1.6	0.05
0.99998	20	5	3	2	0.05
0.98310	20	5	3	3	0.05

Appendix D Ethics Clearance – Modification and extension

Human Research Ethics Committee (Medical)

Research Office Secretariat: Senate House Room S-10005 2nd floor, Tel +27 (0)11-717-1252
Medical School Secretariat: Philip Tobias Building 2nd Floor Tel +27 (0)11-717-2700
Private Bag 3, Wits 2050, www.wits.ac.za Fax +27 (0)11-717-1285

19 August 2015

Ms Dershnee Devan
Brain Function Research Group
Faculty of Health Science
7 York Road
Parktown
2193

Sent by email to: dershnee.devan@wits.ac.za

Dear Ms Devan

Re: **Protocol Ref no: M140877**
Protocol Title: Comparison of Non-Pharmacological Interventions for Reducing Pain in Individuals with HIV.
Principal Investigator: Ms Dershnee Devan

Protocol Amendment

This letter serves to confirm that the Chairperson of the Human Research Ethics Committee (Medical) has approved your amendments, namely, to add another questionnaire and recruit further 60 patients to the study, on the above mentioned protocol, as detailed in your letter dated 09 February 2015.

Thank you for keeping us informed and updated,

Yours Sincerely,

Mr Langutani Masingi
Administrative Officer
Human Research Ethics Committee (Medical)

Appendix E Random number Sequence

Home Games Numbers Lists & Hats Drawings Web Tools Statistics Textbook Tools Learn More Login

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True Random Number Service

Do you own an iOS or Android device? Check out our app!

Random Sequence Generator

Here is your sequence:

4	33	47
55	9	37
6	34	35
40	1	10
35	58	31
3	43	45
7	44	49
19	46	54
20	15	23
51	12	56
17	30	41
14	50	27
8	32	52
59	2	29
42	28	24
30	53	48
13	60	16
11	57	21
38	26	36
5	39	10

Timestamp: 2015-01-24 08:23:56 UTC

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Note: The numbers are generated left to right, i.e., across columns.

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True Random Number Service

Do you own an iOS or Android device? Check out our app!

Random Sequence Generator

Here is your sequence:

68	70	60
67	66	65
61	64	69
63	62	

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Appendix F Information and Consent for research study

INFORMATION SHEET

Comparison of non-pharmacological interventions for managing symptoms in individuals living with HIV.

Good day. I am Dershnee Devan, a student at Wits University. People with HIV suffer from many symptoms that affect their daily lives and I am trying to find out what would be the best way to manage these symptoms. By helping me in this study you will help us find out if there are other ways to treat these symptoms other than using medicine. There will be no procedures like injections and you won't be asked to take any extra medicines.

If you agree to be part of the study, Flo or Tosh would like to ask you some questions. There will be 4 question sheets. These question sheets will ask you how well you are doing in your day-to-day life, whether you feel sad and about your pain. There will also be a physical test which will include some simple physical tasks, for example, walking, reaching and tying a belt. These will test how physically fit you are and whether your physical fitness improves over the time of the study. We will need about 45 minutes. If you agree, we'll talk in a private room in the HIV Clinic where it is quiet, and no-one will be listening. None of the questions will be difficult to answer. You can tell us whether you want us to ask the questions in English, isiZulu or isiXhosa.

After the questions we will find out which group you will be in. You have a 1 in 3 chance of being in each group.

1. One group will come back to see Flo or Tosh every 4 weeks. She will go through the question sheets with you each time and wants to know how you are doing.
2. The next group will have the same and also be given a book about living with HIV.
3. The last group will also see Flo or Tosh, have the book and will be asked to come back every week for 6 weeks to take part in a course at the Occupational Therapy department at the University of Witwatersrand. The course will take 2 hours every week and be on Saturday mornings from 9 am to 11 am. There will be 10 people in the group.

When you come back for follow up, any questions you may have about the information in the book will be answered by me or your treating doctor or nurse.

1. So, Flo or Tosh, will see everybody to go through the question sheets again 1, 2, 3, 6 and 12 months from now.

You will be given taxi fare for these follow up visits so that you do not have to spend any of your own money to come to the hospital. I will send you sms reminders to make sure you don't forget your appointment for the follow up visit. At these follow up visits Flo or Tosh will ask you the same questions as before.

I need people like you to help me with my research, but if you don't want to be part of the research, you can just tell me no at any time. I'm part of the University, but I'm not part of the hospital. The doctors and nurses looking after you will look after you just the same, whether you agree to help me or not. I won't tell them if you say yes or no. All the answers you give will be kept confidential and will be seen by me, the people helping me and yourself only. We will not show it to the doctors or nurses looking after you. I am going to give you a number like a PIN number so that people looking at your answers won't know your name. When I finish my research I will combine everybody's answers and show other researchers, doctors and nurses. However, your individual results won't be seen by anybody. When the research is completed and if it is shown that one of the treatments was effective in helping people with HIV do better in their day-to-day activities you will be given a chance to have this treatment if you would like to have it.

A group of staff at the University who look after patients' rights have checked my study to make sure it is fair and treats patients well. If you want to know more about your rights when you are taking part in research you can contact Professor Cleaton-Jones on (011) 717 2301.

Thank you for thinking about taking part in my research. Please read this sheet and have a think before signing to say that you agree to join in. If you have any questions, please ask me at any time. If I'm not in the clinic, please contact me, Dershnee on 011 717 3726, or you can visit me in my office: room no. 8, Occupational Therapy Department, Wits Education Campus, St Andrews Rd, and Parktown.

Yours sincerely,

Dershnee Devan

CONSENT FORM PARTICIPANT ID:

A comparison of non-pharmacological interventions in reducing symptoms in individuals infected with HIV

I, _____, have been told about research that is trying to find out how effective different treatments that don't use medicine for HIV positive people are.

I understand that I shall be asked questions about how HIV affects my life.

1. I understand that I will be asked to perform a set of physical tasks to see how fit I am.

1. I agree to come back for 2 hours, once a week for 6 weeks on Saturday morning between 9 am and 11am if I am put in the course group.

2. I agree to come back for appointments to see how I am doing 1, 2, 3, and 6 and 12 months from now, whichever group I am put in.

I agree to helping with the research by answering questions, performing a fitness test and participating in the groups offered as part of the research. I know that nobody is forcing me to do this and I can stop helping at any time, without anyone blaming me.

_____ _____

Signed (subject) Date

_____ _____

Signed (researcher) Date

CONSENT FORM: MULTIMODAL GROUP PARTICIPATION

PARTICIPANT ID:

A comparison of non-pharmacological interventions in reducing symptoms in individuals infected with HIV

I, _____, have been told about research that is trying to find out how effective different treatments that don't use medicine for HIV positive people are.

I understand that I shall be asked questions about how HIV affects my life.

3. I understand that I will be asked to perform a set of physical tasks to see how fit I am.

4. I agree to come back for 2 hours, once a week for 6 weeks on a Saturday morning between 9am and 11am.

5. I agree to come back for appointments to see how I am doing 1, 2, 3, 6 and 12 months from now.

I agree to helping with the research by answering questions, performing a fitness test and participating in the groups offered as part of the research. I understand that all the information that is shared in the group sessions will remain confidential and restricted to those people who participate in the group.

I know that nobody is forcing me to do this and I can stop helping at any time, without anyone blaming me.

_____ _____

Signed (subject) Date

_____ _____

Signed (researcher) Date

Appendix G ACSM Screening Questionnaire

AHA/ACSM Health/Fitness Facility Preparticipation Screening Questionnaire

Assess your health needs by marking all *true* statements.

History

You have had:

___ 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

*If you marked any of the statements in this section, consult your physician or other appropriate healthcare provider before engaging in exercise. You may need to use a facility with a **medically qualified staff**.*

Symptoms

___ You experience chest discomfort with exertion.
___ You experience unreasonable breathlessness.
___ You experience dizziness, fainting, blackouts.
___ You take heart medications.

Other health issues

___ You have diabetes
___ You have or asthma other lung disease.
___ You have burning or cramping in your lower legs when walking short distances.
___ You have musculoskeletal problems that limit your physical activity.
___ You have concerns about the safety of exercise.
___ You take prescription medication(s).
___ You are pregnant.

Cardiovascular risk factors

___ You are a man older than 45 years.
___ You are a woman older than 55 years, you have had a hysterectomy, or you are postmenopausal.
___ You smoke, or quite within the previous 6 mo.
___ Your BP is greater than 140/90.
___ You don't know your BP.
___ You take BP medication.
___ Your blood cholesterol level is >200 mg/dL.
___ You don't know your cholesterol level.
___ You have a close blood relative who had a heart attack before age 55 (father or brother) or age 65 (mother or sister).
___ You are physically inactive (i.e., you get less than 30 min. of physical activity on at least 3 days per week).
___ You are more than 20 pounds overweight.

*If you marked two or more of the statements in this section, you should consult your physician or other appropriate healthcare provider before engaging in exercise. You might benefit by using a facility with a **professionally qualified exercise staff** to guide your exercise program.*

___ None of the above is true.

You should be able to exercise safely without consulting your physician or other healthcare provider in a self-guided program or almost any facility that meets your exercise program needs.

Balady et al. (1998). AHA/ACSM Joint Statement: Recommendations for Cardiovascular Screening, Staffing, and Emergency Policies at Health/Fitness Facilities. *Medicine & Science in Sports & Exercise, 30*(6). (Also in: *ACSM's Guidelines for Exercise Testing and Prescription*, 7th Edition, 2005. Lippincott Williams and Wilkins http://www.lww.com)

www.acsm-msse.org/pt/pt-core/template-journal/msse/media/0696c.htm

Positive Living



Name: _____

Positive Living

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/he has been trained in all the information you will be going through. She/he has also been trained by a physiotherapist or occupational therapist that specializes in HIV/AIDS in safe ways to exercise and in relaxation techniques.

Week 1: Self-Management and Exercise

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?

1. First decide what you are going to do *this week*
2. 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:

1. *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.

2. *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.

3. *When will you do it?*

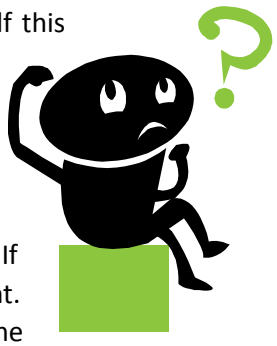
   Then you must decide on exactly which day you are going to do the activity and at what time of the day. Maybe it is better to invite your neighbour for tea in the morning because you get tired in the afternoon. Or if you feel sick in the morning from your medicines maybe it is better to invite your neighbour for afternoon tea. Or maybe your neighbour works and you need to invite them for tea at the weekend.

4. *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.

5. *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:

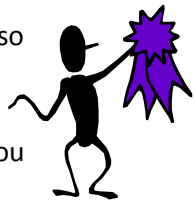
Now, write your plan down and put it somewhere you will see it every day. There is an action plan form at the end of this section and 5 more at the back of this book. Use them every week you are doing this course. You can always draw more of them to keep working on your plans in the future.

A good action plan is:

1. Something I want to do
2. Something I can expect to do this week
3. Is specific
4. Answers the questions: What? How much? When? How often?
5. I am confident that I can achieve with a score of at least 7 out of 10.

Now ...sy. It help...g. 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:

1. Sets goals
2. Makes a list of ways to achieve those goals
3. Makes action plans to achieve the goals
4. Carries out the action plans
5. Checks on their progress every week
6. Can change the action plan if there are problems
7. Gives themselves a reward for achieving their goals

Use these
o discuss
exercise – use the "Action Plan Form" at the end of this section to plan what exercise you are going to do this week.



Exercise

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:

1. Improving mood
2. Strength
3. Improving sleep
4. Concentration and memory
5. Heart and lung health
6. Decreasing body fat
7. Digestion
8. Increasing confidence to self-manage chronic illness.



Do not exercise if:

1. You have a fever
2. You are dizzy
3. You have been vomiting
4. You have diarrhoea
5. Your joints have suddenly become swollen
6. 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.

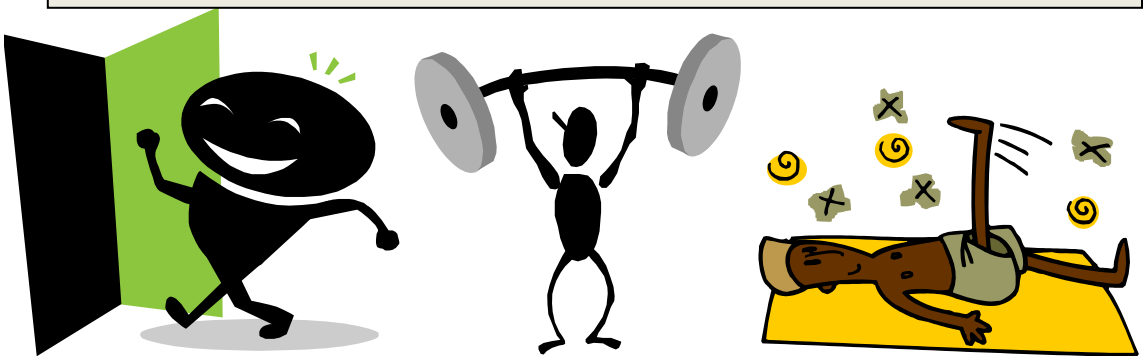
What kind of exercise should you do?

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:

1. Endurance exercise which makes you breathe harder (sometimes called aerobic)
2. Strengthening exercise which makes you stronger



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 to 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:

1. Set a clear goal using the steps outlined in "How to be a successful self-manager"
2. Choose exercise or activity that you want to do and that is fun
3. Set a specific time and place to do your exercise
4. 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)
5. 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)
6. Keep track of your progress using the exercise diaries in this workbook.
7. Start – don't wait, start now. Begin gradually and proceed slowly

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:

1. Move slowly and gently. *Do not* use jerking or bouncing movements as these will make your muscles shorter and tighter.

2. Stretch to the point of *tension* in a muscle and hold for 20 seconds before you relax

3. Don't push until it hurts, *stretch to tension not pain*

4. Start off with 5 repetitions of each exercise. After 1 week increase it to 7, after another week increase to 10.

5. Always do the *same number* of exercises on the left side and the right side of your body

6. *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.

7. Use the *two hour rule*. If you have increased symptoms for more than two hours

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.

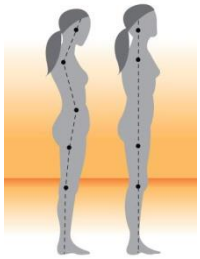
How will you know you are improving in your exercises? For the flexibility and strength exercises it is easy to feel the improvements as you will feel that moving is easier and you are stronger and can lift heavier items. For some people it is harder to know if you are improving with the endurance exercises. 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

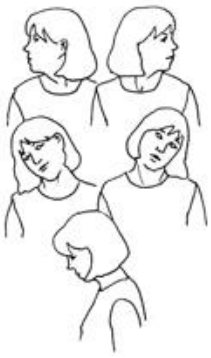
This is a 20 minute exercise routine which is safe for people living with HIV. This routine includes exercises which make you stronger (strength exercises), more flexible (stretching exercises) and fitter (endurance exercises).

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.

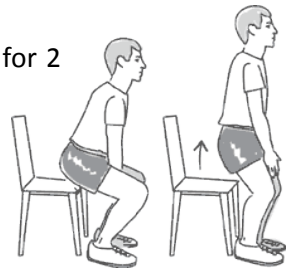


4. March on the spot for 2 minutes – 30 steps normal, 30 steps lift your knees up as high as you can. Keep changing every 30 steps.

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.

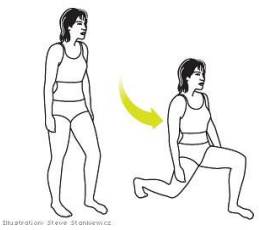


7. Lie down on the floor with your knees bent and your arms crossed on your chest. Lift your head to put your chin on your chest, now lift your shoulders off the ground. Slowly lower down. Keep going for 2 minutes.



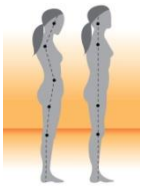
8. March on the spot for 2 minutes – 30 steps normal, 30 steps lift your feet up as high as you can (try to kick your buttocks). Keep changing every 30 steps.

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

	I Plan to…..	**I did…..**
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

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

Week 2: Managing Common Symptoms of HIV

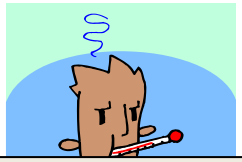
When something that is happening to our bodies that is unusual or not right, we develop symptoms. Symptoms include things like having a fever or temperature, feeling nauseous, vomiting, feeling tired, having pain, having a skin rash, coughing or struggling to breathe, feeling depressed and many, many 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:

Fever	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.
Altered mental status	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.
Severe	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.
Typical	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

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 cans 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:

1. Do you feel down most of the time?
2. Do you lack enjoyment with fun things like music, soccer or chocolate?
1. Do you try to find peace by overeating?
2. Or do you lack appetite and lose weight?
1. Do you sleep badly at night?
2. Do you struggle to get up in the mornings?
1. Do you feel angry and agitated very quickly?
2. Do you feel very passive?
3. Do you lack energy every day?
1. Do you struggle to concentrate?
2. Is it difficult to make decisions about simple matters?
3. Do you feel guilty?
4. Do you feel worthless sometimes?

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?

1. *Black or bloody stools*
2. *Severe, steady stomach pain*

Yes → Go to the clinic now

No ↓

Do you have any signs of dehydration?

1. *Extreme thirst*
2. *Very dry mouth*
3. *Dark urine*
4. *Lightheadedness*

Yes → Go to the clinic today

No ↓

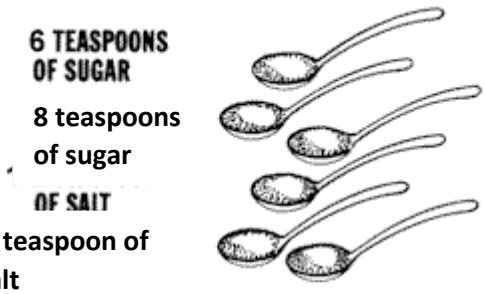
Are you taking antibiotics?

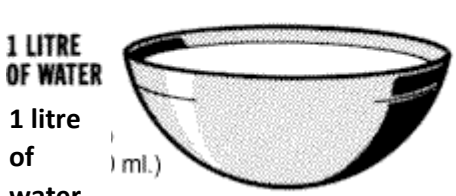
Yes → Go to the clinic

No ↓

Yes

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.





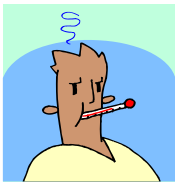
Making a ***glucose drink*** is the most effective treatment for diarrhoea. Make this by filling a clean one-litre bottle with clean water from a tap or boiled water if you are not sure that the water is clean. Add 8 teaspoons of sugar and half a teaspoon of salt to the water and mix it well. You can 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.

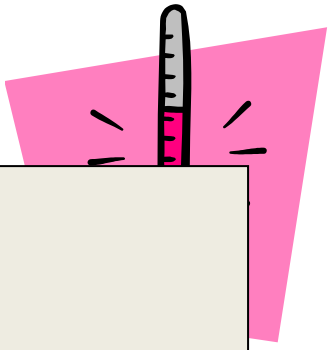
If you have diarrhoea you might not feel like eating but skipping food is not a good idea. Try plain foods like dry toast white rice noodles, mashed potatoes or white bread. Eat any food that doesn't make you feel sick. Make sure you wash your hands before and after handling food. Usually diarrhoea will 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.



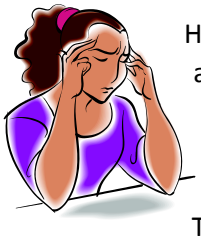


Fever Action Chart:

Do you have a fever and?		
5. Neck stiffness (you can't bend your neck to put your chin on your chest) *6. Extreme tiredness or feel confused* *7. Fitting or seizures* *8. 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*? *1. Headache* *2. Sore throat* *3. Cough* *4. Diarrhoea*	Yes →	See the action plan for that problem

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. Paracetomol (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:

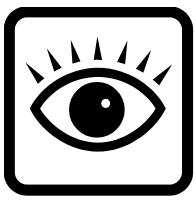
Do you have a *fever and neck stiffness* with your headache?	Yes →	Go to the clinic now
No ↓		
Do you have any of these with your headache?		
1. *Difficulty moving your arms or legs* 2. *Difficulty with seeing* 3. *Difficulty speaking (slurring)*	Yes →	Go to the clinic now
No ↓		
Has your headache lasted more than 3 days?	Yes →	Go to the clinic
No ↓		

Home treatment for Headaches: Paracetomol 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 *blindness* (part or total) come on *suddenly* in one or both eyes or is *the loss of vision severe*?	Yes →	Go to the clinic now
No ↓		
Is your CD4+ count more than 200	Yes →	Go to the clinic
No ↓		
Have you had *gradual loss of vision equally in BOTH* eyes	Yes →	Go to the clinic
No ↓		

Nausea and Vomiting:



Many of the worries about nausea and vomiting are the same as for diarrhoea. Medicines are the 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.



Nausea and Vomiting Action Chart:

Do you have any of these?

1. *Black or bloody vomit*		
2. *Severe steady stomach pain*	Yes →	Go to the clinic now
3. *Headache with a stiff neck (you can't put your chin on your chest)*		
No ↓		

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.

Shortness of Breath Action Chart:

Do you have *shortness of breath at rest or with very little activity*?

Yes → Go to the clinic now

No ↓

Do you have a *dry cough* or *fever* with your shortness of breath?

Yes → Go to the clinic now

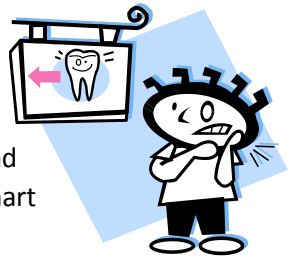
No ↓

Treat at home and go to the clinic

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 very 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

Home treatment for a sore throat and mouth: Drinking cool liquids and taking painkillers like paracetomol 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:



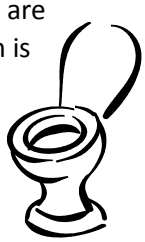
There are many skin problems which can affect people living with HIV/AIDS. Very few of these problems are dangerous but because they can be seen they can be very upsetting. Being able to see these might make you feel unattractive or have low self-confidence, they often last a long time and can constantly 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.

Skin Problems Action Chart:

Do you have a rash which is *painful* 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 *fever*?	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		

Hom ...tions deve... 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 *fever, vomiting, back pain, shaking chills* as well as *painful or frequent or bloody urination*?

Yes → Go to the clinic today

No ↓

Could you be pregnant?

Yes → Go to the clinic today

No ↓

Do you also have a *new irritating vaginal discharge*?

Yes → Go to the clinic today

No ↓

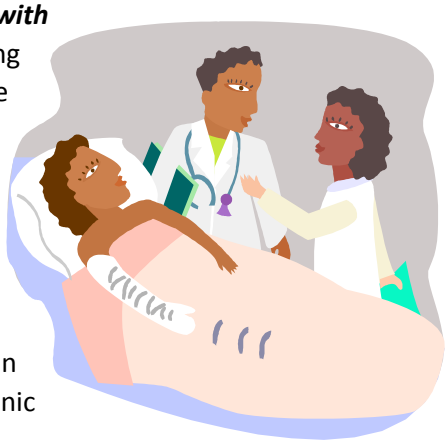
Do you have pain in your stomach (abdomen)

Yes

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 24hours 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

	I Plan to…..	**I did…..**
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

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 confident | | | | | | | | | | Totally confident

1 2 3 4 5 6 7 8 9 10

Keep a record of

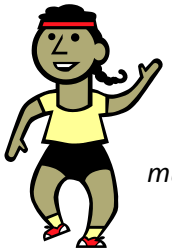
Exercise Diary

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?)*

	Exercise Planned	**Exercise I did...**	**How did I feel? Do you need to change anything?**
e.g.	*20 mins in a.m. after breakfast and in p.m. after supper*		*Very tired by the second session, I'm going to cut it down to morning only for this week.*
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			

Week 3: Stress Management



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 stressed we 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:

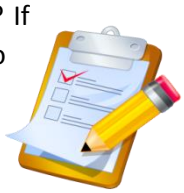
1. Dealing with the cause of the stress



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 breath 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:

1. You feel you are getting tense or irritable or you are worried
2. You feel you are in pain
3. 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:

4. Go to sleep at the same time every day
5. Have a bedtime routine
6. Do relaxation before going to sleep
7. Use your bed only for sleeping or relaxing
8. Have a morning routine

7.



arly 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:

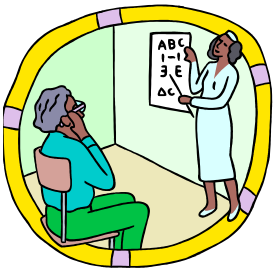
9. Decreases stress
10. Helps us sleep better
11. Decreases pain
12. *Makes us healthy and decreases our chances of developing other illnesses*

8. 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 has not worked at all.



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!

Relaxation

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 finger tip 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 finger tips... 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.

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

Monday
Tuesday
Wednesday
Thursday
Friday
Saturday
Sunday

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 *<u>this week</u>* 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?)*

	Exercise Planned	**Exercise I did...**	**How did I feel? Do you need to change anything?**
e.g.	*20 mins in a.m. after breakfast and in p.m. after supper*		*Very tired by the second session, I'm going to cut it down to morning only for this week.*
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			

Week 4: Pain



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.

<u>Checking the cause of pain</u>

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.

<u>What can you do for pain?</u>

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

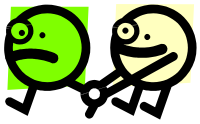
a self-manager who understands about their treatment and, having support can help manage your pain. We are now going to talk about different things that you can do to help decrease pain.

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:

9. Paracetomol (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.
10. 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.

11. Anti-inflammatories like indomethacin (indocid), dicolfenac (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.
12. Paracetomol and Codeine is stronger than paracetomol on its own. If you have been using paracetomol on its own and taking it as the nurse or doctor told you but your pain is not getting better they may give you paracetomol with codeine.
13. Dextropropxyphene (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.
14. Codeine phosphate is much stronger and can only be prescribed by a doctor. This medicine can make you sleepy and can cause constipation.
15. 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

13. Pain is one of the most common symptoms people living with HIV/AIDS experience
14. Pain can be caused by the virus, by tense muscles, by weak muscles and stiff joints.
15. Pain can be caused by and made worse by stress and worry

Action Plan Form - Pain

Think about one pain which you commonly experience. Use this action plan form to develop a plan

When I have pain I plan to….. I did…..

Monday
Tuesday
Wednesday
Thursday
Friday
Saturday
Sunday

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:

_____*(what)*
_____*(how much)*
_____*(when)*
_____*(how many?)*

How confident are you that you can complete this action plan?

_____

Not at all confident | | | | | | | | | | Totally confident
1 2 3 4 5 6 7 8 9 10

Keep a record of

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 <u>*this week*</u> 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?)*

	Exercise Planned	**Exercise I did...**	**How did I feel? Do you need to change anything?**
e.g.	*20 mins in a.m. after breakfast and in p.m. after supper*		*Very tired by the second session, I'm going to cut it down to morning only for this week.*
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			

Week 5: Eating Well

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.



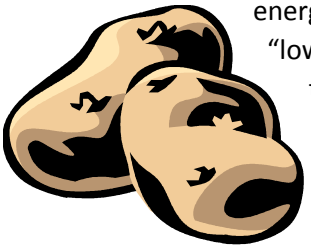
One of the important steps for eating well is to eat small meals or snacks often through the day. It is best to try and eat 3 meals a day and have another 2 snacks a day. This means that we should eat 5 times a day; these meals do not all need to be big meals, a snack might be some fruit, nuts or sour 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 are 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.

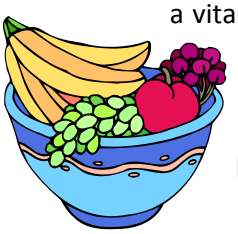


Fruits and Vegetables

Spinach-Morogo-Pumpkin-Green Peppers-Lettuce-Beans-Squash-Carrots-Tomatoes
Peaches-Apricots-Oranges-Naartjies-Avocados-Paw Paw-Mango-Guavas-Watermelon

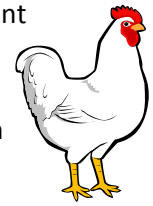


The second most important groups of food which we need are the fruits and vegetables. We should eat at least one fruit and one vegetable with every meal and aim to have at least 7 portions of fruits and vegetables every day. Fruits and vegetables supply vitamins and substances which are important for 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

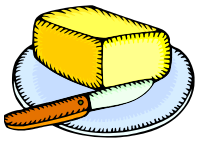
Beef-Pork-Chicken-Fish-Mutton-Lamb-Eggs-Milk products-Beans-Grains-Nuts



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

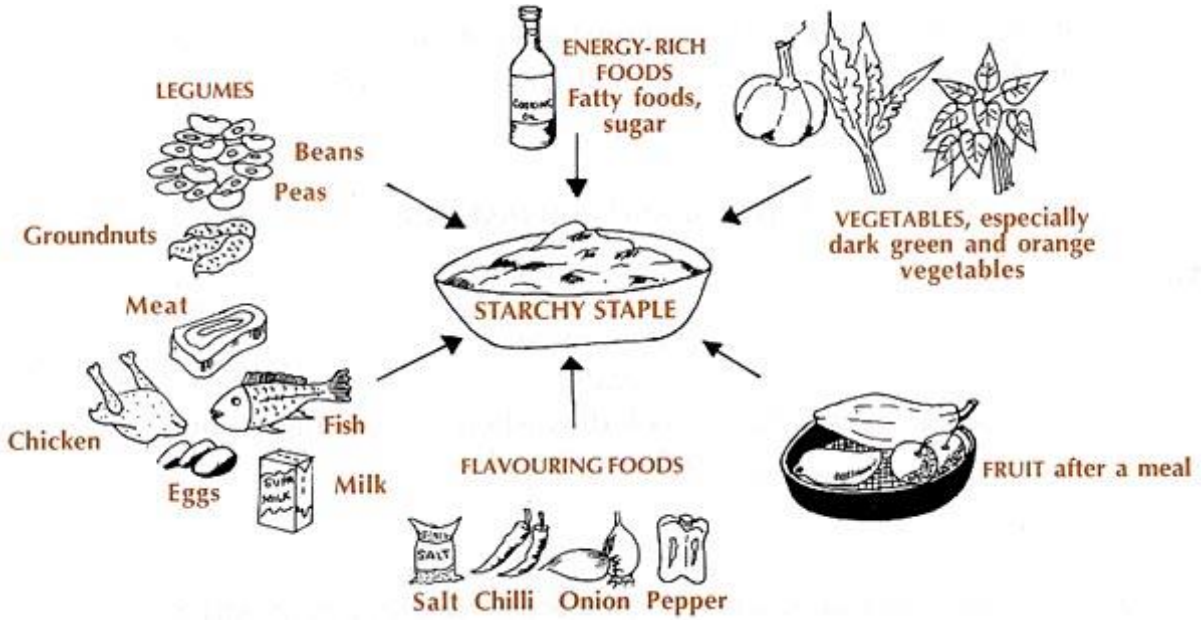
Butter-Lard-Margarine-Cooking oils-Cream-Mayonnaise



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"

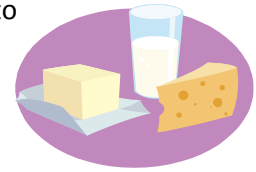
Wanting to vomit when you eat can be because of an infection or a side effect of the medication. Eating smaller meals helps (5 or 6 meals a day) – it is important to know that nausea or the feeling that you are going to vomit is often worse when your stomach is empty. Food with lots of spices or fats 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

18. Try to eat at least 5 times a day – 3 meals and 2 snacks.
19. Eat energy food first.
20. Keep snacks with you to eat as soon as you feel hungry.
21. Drink 6 glasses of juice and water a day.

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

23. 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.
24. Don't buy food if the packaging is damaged
25. 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.
26. 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.
27. 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

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:

	I Plan to…..	**I did…..**
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

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

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 <u>*this week*</u> 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?)*

	Exercise Planned	**Exercise I did...**	**How did I feel? Do you need to change anything?**
e.g.	*20 mins in a.m. after breakfast and in p.m. after supper*		*Very tired by the second session, I'm going to cut it down to morning only for this week.*
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			

Week 6: Continuing as a Successful Self-Manager

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:

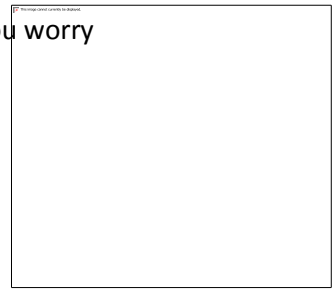
1) _____

_____

_____

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:

_____

_____

My plan to manage this if it happens is to:

_____
_____
_____
_____
_____
_____
_____
_____
_____*(what, who, how, when?)*



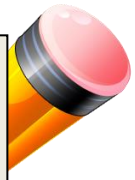
How confident are you that you can complete this action plan? *(remember you are aiming for 7 out of 10 on the confidence line)*

_____

Not at all | | | | | | | | | |
Totally

Moving forward:

Over the last 6 weeks you have learnt many things about how to live with a chronic illness like HIV/AIDS. You have learnt about the disease and how to be a successful self-manager. This does not mean that you should be managing your health on your own. What it does mean is that you now have the ability to manage your health and your life as part of the health team. Remember you are not alone but are part of a team of people whose aim is to help you get the most out of life. We encourage you to keep using the skills you have learnt in this workbook to live positively. There are extra "Action Plan Forms" and "Exercise Diaries" in the back of the workbook for you to use. Try to keep using these forms to help you remain active and give you a sense of purpose and accomplishment in your life. Being active and involved, using the skills you have learnt in this workbook are important steps in helping you achieve the best quality of life you can. In the box write down some of the important changes you have made in your life over the past few weeks.



Changes I have made in my life:

Now, your final task is to think about changes you still want to make in your life. Remember, this is about getting the most out of life, increasing your quality of life. Are there still some things missing in your life, things that you would still like to be able to do? In the box below, write down some of the things that are still missing. You can use this list to keep working on your goals from now on.

Things that are still missing in my life:

You have now completed this workbook. By working through this workbook you made an important commitment to yourself. You have chosen to spend time looking after yourself and you have taken steps to overcome the many challenges that people living with HIV/AIDS face. Do not put this workbook away; keep it somewhere safe where you will be able to review it from time to time. We all forget things at times and it is useful to be able to look back and remind ourselves of things we may have forgotten. We can also look back and see how far we have come. We hope that the knowledge and the skills you have learnt by using this workbook will continue to have a positive effect on your life.

Useful Organisations:

Treatment Action Campaign (TAC) (http://www.tac.org.za)

Johannesburg 011 872 1405

Family and Marriage Society of South Africa (FAMSA) (http://www.famsa.org.za)

Johannesburg 011 892 4272

AIDS consortium (http://www.aidsconsortium.org.za/)

(011) 403-0265

Aids Law Project (ALP) (http://alp.immedia.co.za/)

(011) 356-4100

National Association of People living with HIV/AIDS (NAPWA) (http://www.napwasa.org.za/)

Johannesburg 0846964964

Additional Reading

The information is 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 (3rd edition) Bull Publishing Company, Boulder Colorado2005

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

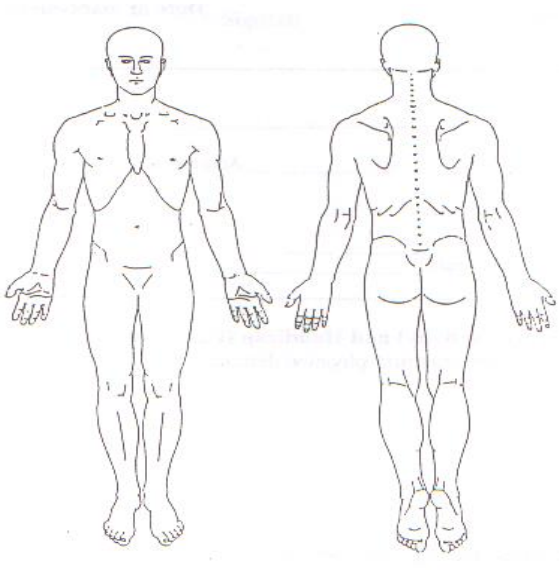
Appendix I Brief Pain Inventory

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

16. 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 Relief										Complete 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 interfere										Completely interferes

B. ***Mood***

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

C. ***Walking Ability***

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

D. ***Normal Work*** (includes both work outside the home and housework)

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

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

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

F. ***Sleep***

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

G. ***Enjoyment of life***

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

Scoring:
Pain Severity Score = Mean of items 3–6 (pain at its worst, pain at its least, average)
Pain Interference Score = Mean of items 9A–9G (interference of pain with: general activity, mood, walking, normal work, relations, sleep, enjoyment of life)

Appendix J Becks Depression Inventory II

Roche

V 0477

Beck Depression Inventory

CRTN: _____ CRF number: _____

Page 14 patient inits: _____

Baseline

BDI-II

Date:

Name: _____ Marital Status: _____ Age: _____ Sex: _____

Occupation: _____ Education: _____

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness

0 I do not feel sad.
1 I feel sad much of the time.
2 I am sad all the time.
3 I am so sad or unhappy that I can't stand it.

2. Pessimism

0 I am not discouraged about my future.
1 I feel more discouraged about my future than I used to be.
2 I do not expect things to work out for me.
3 I feel my future is hopeless and will only get worse.

3. Past Failure

0 I do not feel like a failure.
1 I have failed more than I should have.
2 As I look back, I see a lot of failures.
3 I feel I am a total failure as a person.

4. Loss of Pleasure

0 I get as much pleasure as I ever did from the things I enjoy.
1 I don't enjoy things as much as I used to.
2 I get very little pleasure from the things I used to enjoy.
3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

0 I don't feel particularly guilty.
1 I feel guilty over many things I have done or should have done.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.

6. Punishment Feelings

0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.

7. Self-Dislike

0 I feel the same about myself as ever.
1 I have lost confidence in myself.
2 I am disappointed in myself.
3 I dislike myself.

8. Self-Criticalness

0 I don't criticize or blame myself more than usual.
1 I am more critical of myself than I used to be.
2 I criticize myself for all of my faults.
3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

10. Crying

0 I don't cry anymore than I used to.
1 I cry more than I used to.
2 I cry over every little thing.
3 I feel like crying, but I can't.

_____ Subtotal Page 1

Continued on Back

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11. Agitation

0 I am no more restless or wound up than usual.
1 I feel more restless or wound up than usual.
2 I am so restless or agitated that it's hard to stay still.
3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0 I have not lost interest in other people or activities.
1 I am less interested in other people or things than before.
2 I have lost most of my interest in other people or things.
3 It's hard to get interested in anything.

13. Indecisiveness

0 I make decisions about as well as ever.
1 I find it more difficult to make decisions than usual.
2 I have much greater difficulty in making decisions than I used to.
3 I have trouble making any decisions.

14. Worthlessness

0 I do not feel I am worthless.
1 I don't consider myself as worthwhile and useful as I used to.
2 I feel more worthless as compared to other people.
3 I feel utterly worthless.

15. Loss of Energy

0 I have as much energy as ever.
1 I have less energy than I used to have.
2 I don't have enough energy to do very much.
3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

0 I have not experienced any change in my sleeping pattern.
1a I sleep somewhat more than usual.
1b I sleep somewhat less than usual.
2a I sleep a lot more than usual.
2b I sleep a lot less than usual.
3a I sleep most of the day.
3b I wake up 1–2 hours early and can't get back to sleep.

17. Irritability

0 I am no more irritable than usual.
1 I am more irritable than usual.
2 I am much more irritable than usual.
3 I am irritable all the time.

18. Changes in Appetite

0 I have not experienced any change in my appetite.
1a My appetite is somewhat less than usual.
1b My appetite is somewhat greater than usual.
2a My appetite is much less than before.
2b My appetite is much greater than usual.
3a I have no appetite at all.
3b I crave food all the time.

19. Concentration Difficulty

0 I can concentrate as well as ever.
1 I can't concentrate as well as usual.
2 It's hard to keep my mind on anything for very long.
3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

0 I am no more tired or fatigued than usual.
1 I get more tired or fatigued more easily than usual.
2 I am too tired or fatigued to do a lot of the things I used to do.
3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

3 4 5 6 7 8 9 10 11 12 A B C D E

_____ Subtotal Page 2
_____ Subtotal Page 1
_____ Total Score

NR15645

Appendix K Euroquol 5D

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	❑

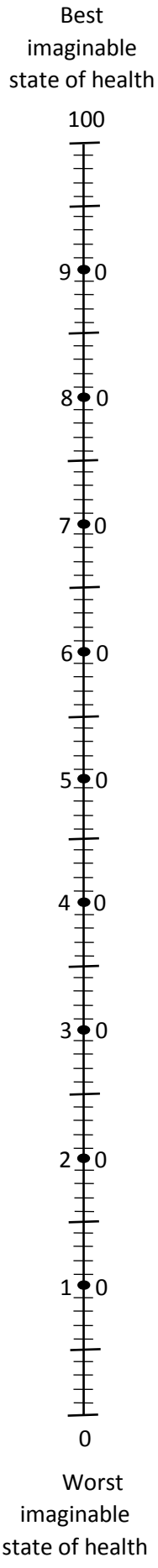
Compared with my general
level of health over the past 12 months,
my state of health today is:

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



Appendix L Self-Efficacy for Managing Chronic Disease 6 item Scale

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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?

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?

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?

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?

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?

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?

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.

1

Appendix M Simmonds Battery of Physical tests

Simmonds Battery of Functional Tests

1. 15 metres (m) walking at preferred speed. For this test, subjects are timed as they walk 7.5 m turn around, and walk back to the starting position at their preferred walking speed.

2. 15 m walk at fastest speed. Subjects are again timed as they walk 8 m, turn around, and walk back to the start as fast as they can.

3. Unloaded forward reach. For this test, subjects stand adjacent to a wall on which a tape measure is positioned horizontally at shoulder height. Subjects reach forward as far as they can and the distance reached is measured in centimetres (cm).

4. Timed, repeated sit-to-stand. Subjects sit in a standard chair and are then timed as they stand up and then sit back down, twice. The test is repeated after a brief rest and the average time of the two trials is used.

5. Sock test. Subjects sit in a standard chair. They are timed as they put on one loose-fitting sock.

6. Loaded forward reach. For this test, subjects stand adjacent to a wall on which a tape measure is positioned horizontally at shoulder height. They hold a weighted bar (4.46 kg) with both hands close to their body and at shoulder height. They then reach forward as far as they can with the bar in a horizontal position, maintaining their hands at shoulder height. The reach distance is recorded in centimetres.
7. Timed, repeated reach-up. For this test, subjects stand facing a wall and reach up as high as they can with both hands. A mark is placed on the wall at the reached distance. Subjects then reach up and return their hands to their sides three times, as fast as they can.

8. Distance walked in 6 minutes. Subjects walk as far and as fast as they can for 6 minutes. The distance walked is measured in metres at 6 minutes. (Subjects are allowed to rest if and as necessary during the 6-minute period.)

9. Timed belt tie. Patients sit in a standard chair and are timed as they wrap a standard wrap bandage (approximately 1 meter long) around their waist and tie it in front of them.

Reference:

Simmonds MJ, Novy D, Sandoval R. The Differential Influence of Pain and Fatigue on Physical Performance and Health Status in Ambulatory Patients with Human Immunodeficiency Virus. Clinical Journal of Pain 2005;21:200-206.

Appendix N Feedback questionnaire for peer leader participants

1. What did you like about the course?

2. What didn’t you like about the course?

3. Was there anything more you would like to learn that wasn’t in the course?

4. What did you like about the workbook?

5. What didn't you like about the workbook?

6. Is there anything you would like to add or change in the workbook?

Appendix O – Graphs demonstrating modelling of data

Graphs of all histograms and quantile-quantile plots done during modelling of data

Depressive Symptoms

The data from the three intervention groups for BDI scores were tested for normality and found to be slightly skewed to the right as shown in the histogram below.

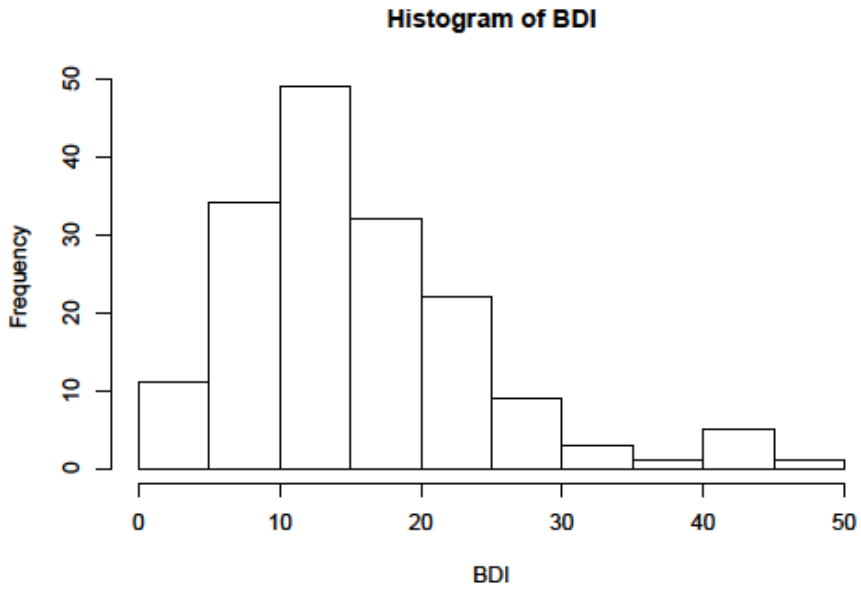


Figure 3.4. Histogram of BDI scores

On a quantile-quantile plot, the data had a heavy upper tail due to the right skew as shown below.

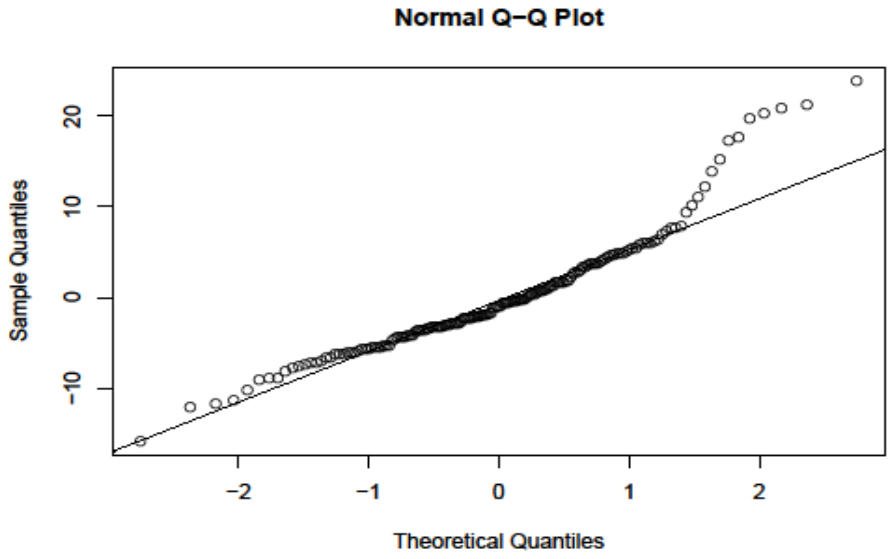


Figure 3.5 Plot of BDI scores

The data were transformed using a square root transform which helped to make the tail less heavy and normalise the data.

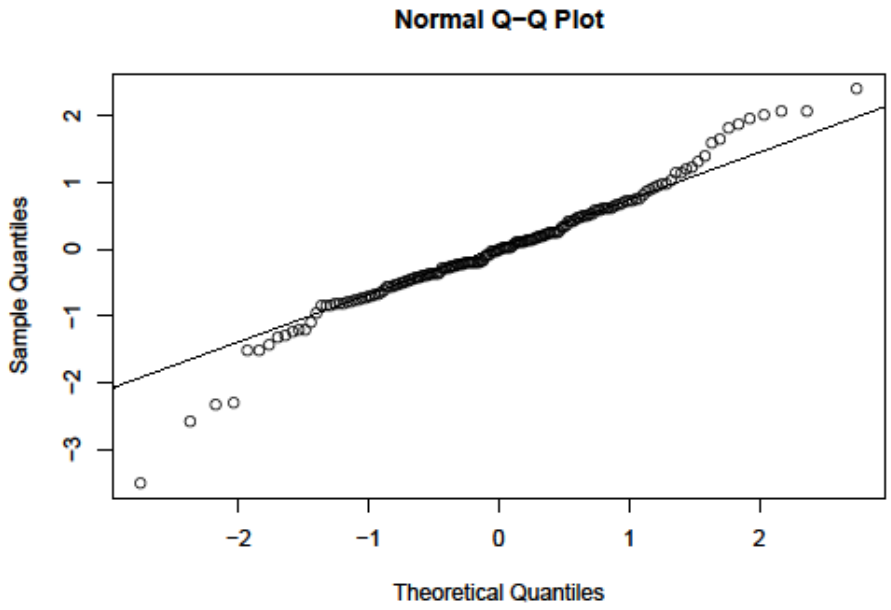


Figure 3.6 Plot of BDI scores after square root transformation

HRQOL Data

The data from the three intervention groups for health related quality of life was tested for normality and found to be slightly skewed to the left as shown in the histogram below.

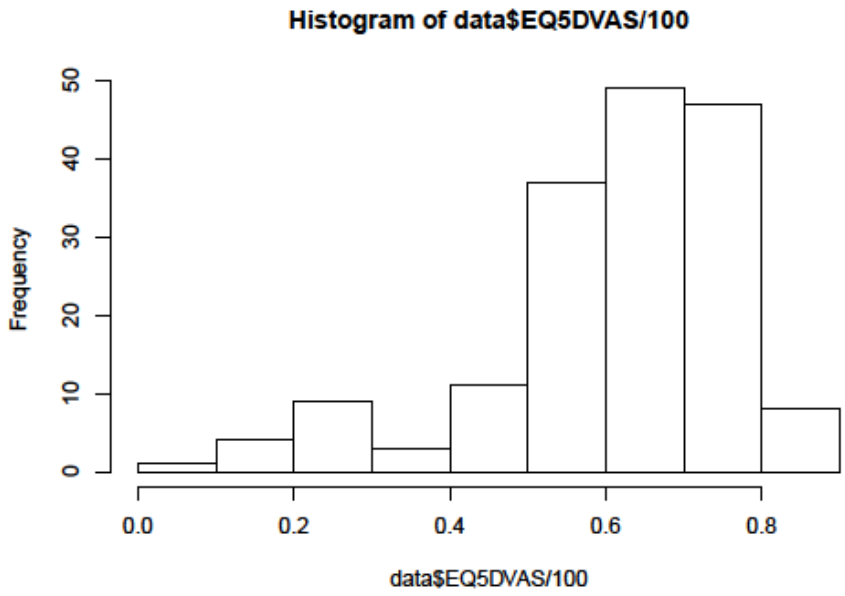


Figure 3.7 Histogram of EQ5D VAS

Normality was also tested with a quantile-quantile plot, which showed the data had a heavy lower tail as shown below.

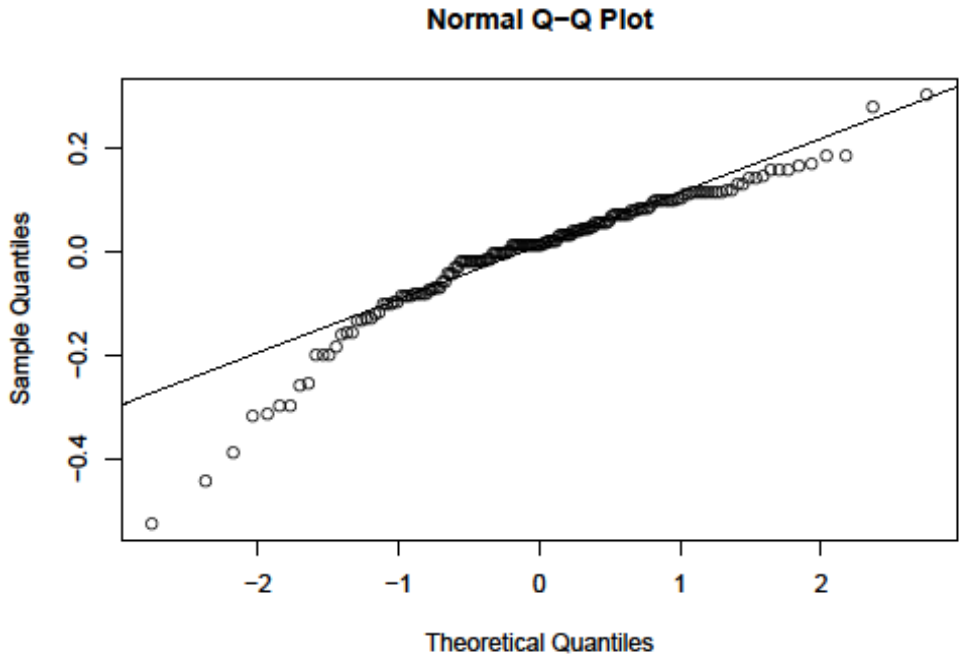


Figure 3.8 Plot of EQ5D VAS

As the data were not normal they were analyzed using a general additive mixed-model (GAMM) with inflated beta distribution.

Preferred walking speed

The data from the three intervention groups for preferred walking speed was tested for normality and found to be slightly skewed to the right as shown in the histogram below.

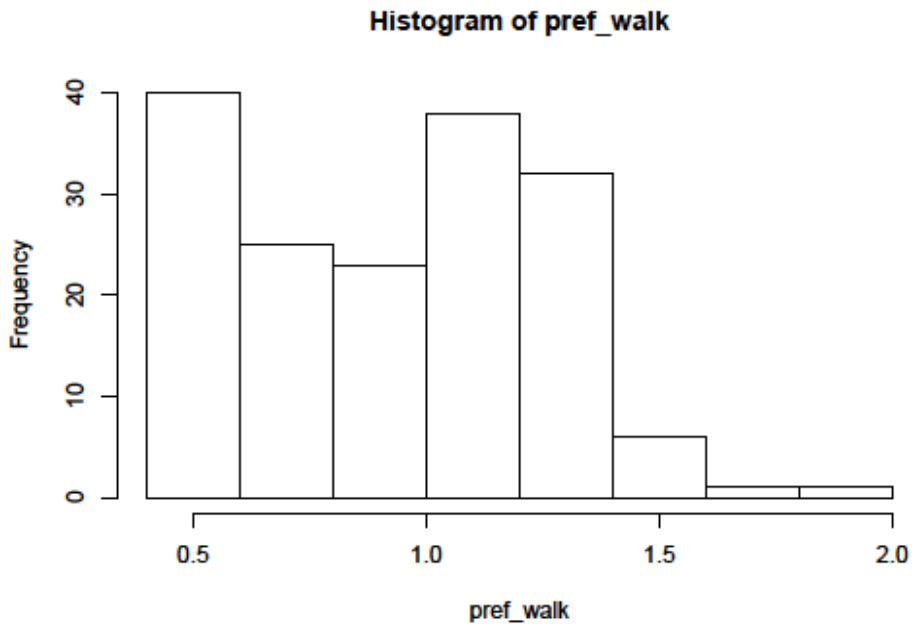


Figure 3.12 Histogram of preferred walking speed

This resulted in the data having a heavy tails due to the right skew in data as shown below.

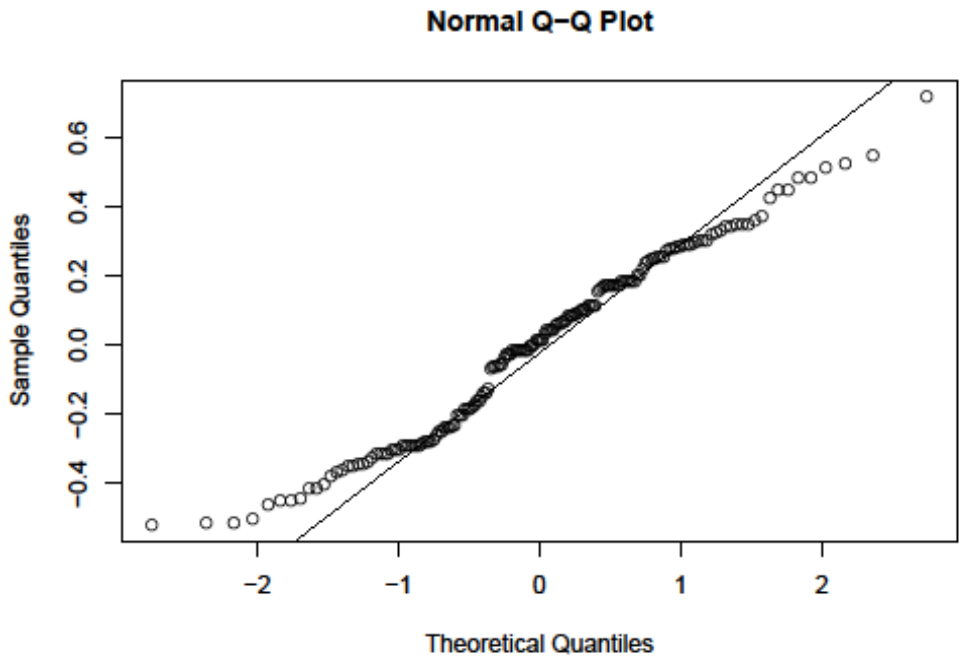


Figure 3.13 Plot of preferred walking speed

The data was transformed using a square root transform which helped to make the tail less heavy and normalise the distribution to account for the right skew in data.

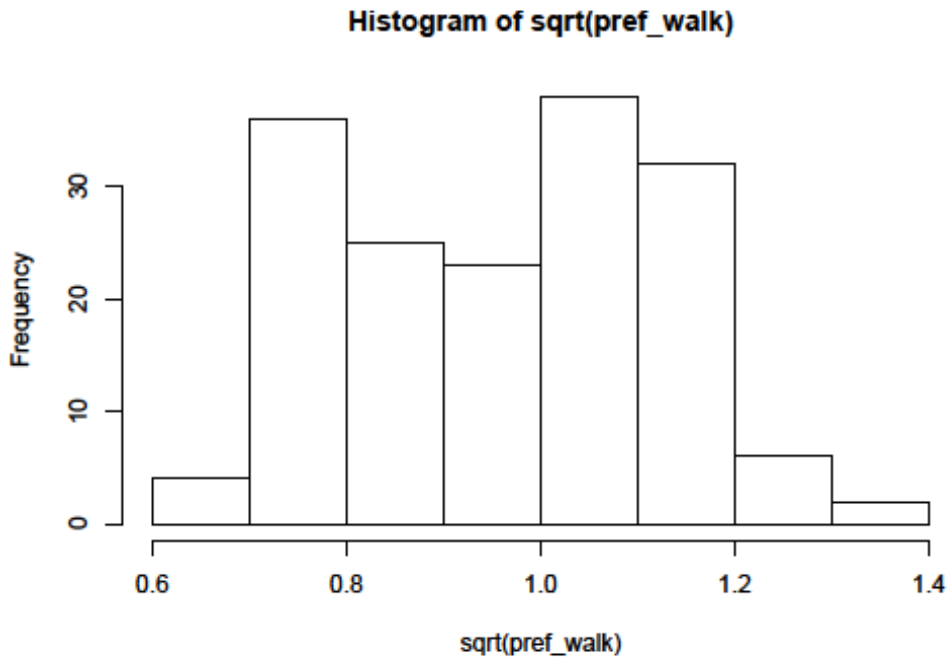


Figure 3.14 Histogram of preferred walking speed with square root transformation

Fastest walking speed

The fast walking speed data was examined for normality and found to a have a slight right skew as shown below.



Figure 3.9 Histogram of fastest walking speed

Although the tails were slightly heavy this was not significant and no further adjustment of data was undertaken.

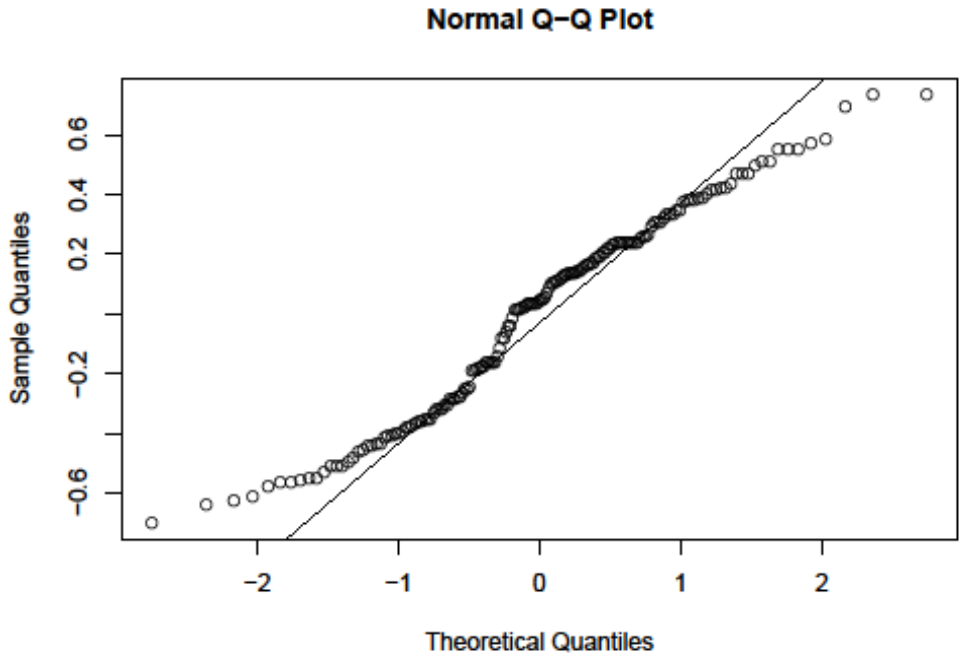


Figure 3.17 Plot of fastest walking speed

6 minute walk test

The distance walked in 6 minutes data was examined for normality and found to a have a slight right skew as shown below.

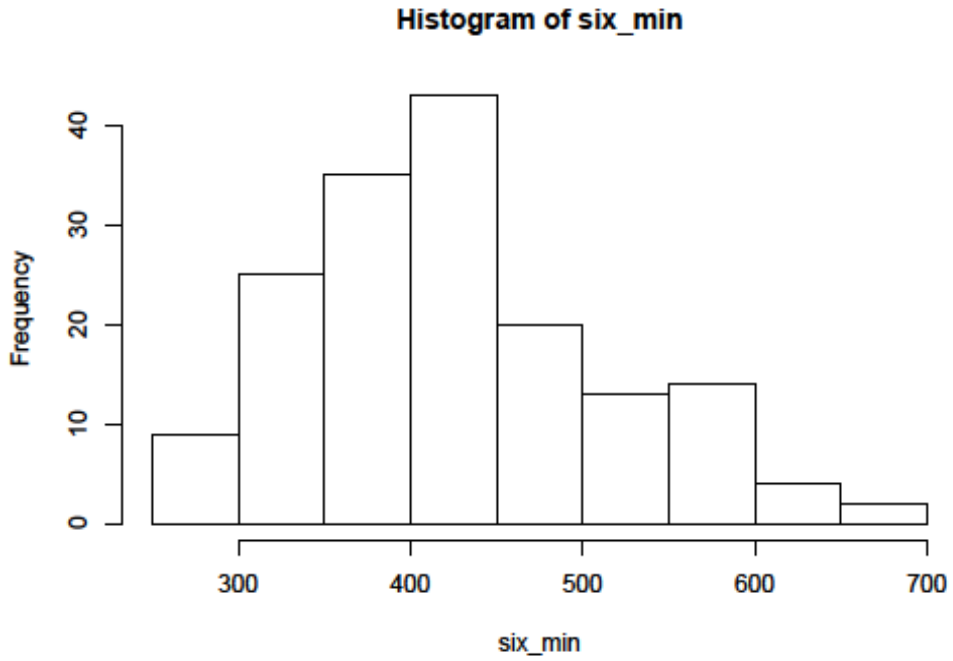
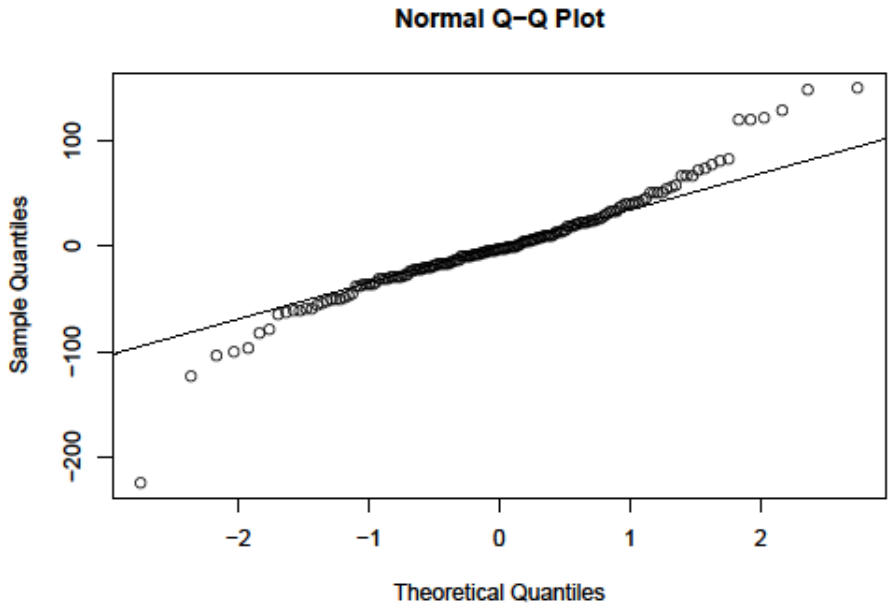


Figure 3.19 Histogram of 6min walk test

Although the tails were slightly heavy this was not significant and no further transformation of data



was undertaken.

Figure 3.10 Plot of 6 min walk test

Unloaded reach test

The unloaded reach test data was examined for normality and found to a have a right skew as shown below.

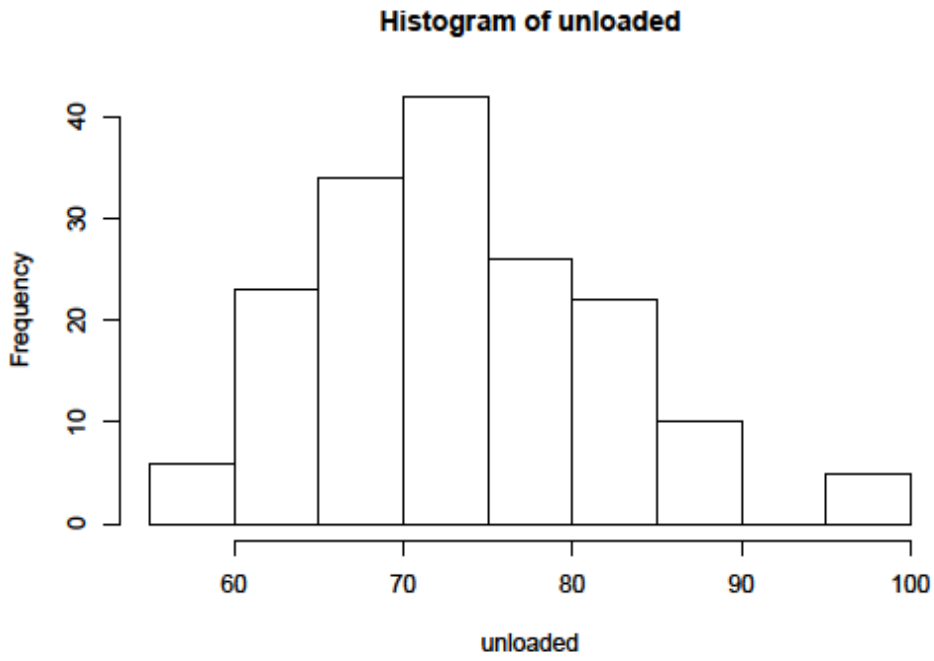


Figure 3.22 histogram of unloaded reach test

This resulted in a heavy upper tail as shown below.

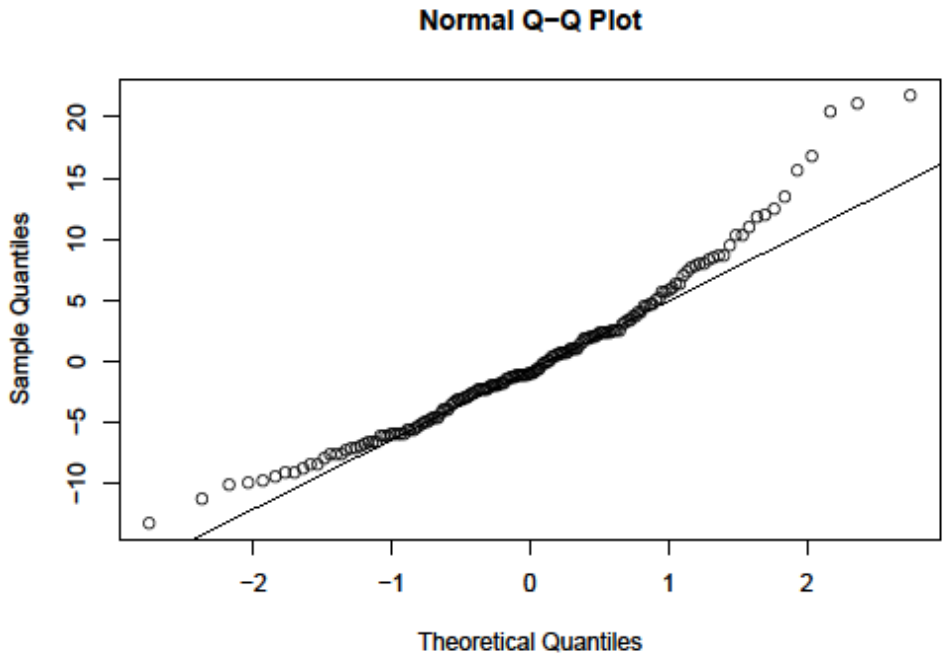


Figure 3.23 Plot of unloaded reach test

A log transformation was used to normalize the data .

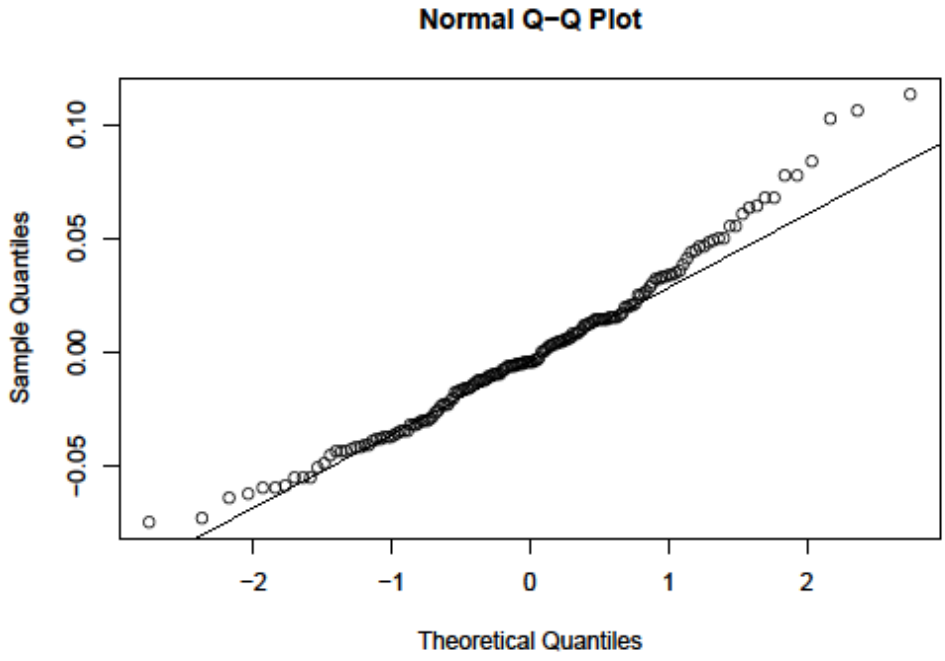


Figure 3.24 Plot of unloaded reach test after log transformation

Loaded reach test

The data for the loaded reach test was fairly normally distributed as shown below.

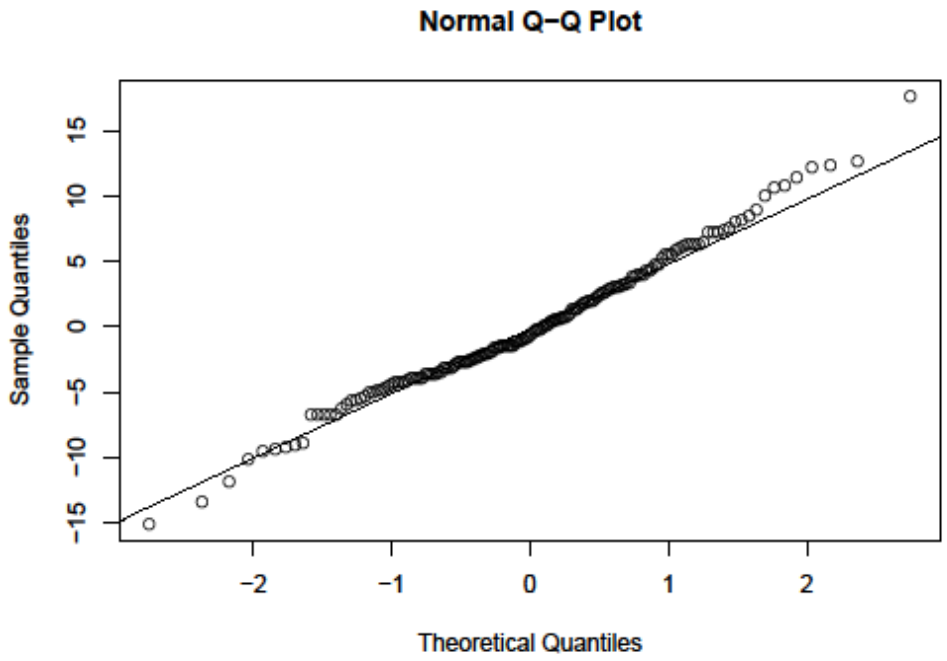
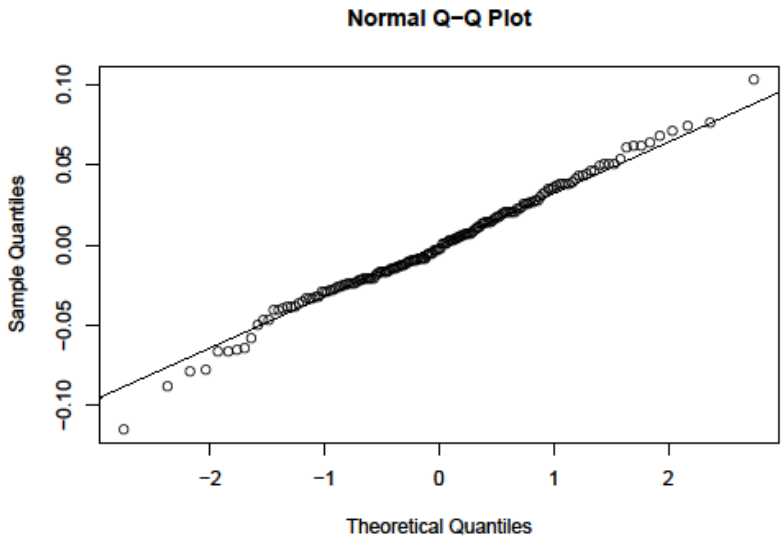


Figure 3.26 Plot of loaded reach test

However a log transformation was used so that the data matched the data from the unloaded reach test.



Appendix P Plagiarism declaration