An evaluation of Palliative care needs for HIV patients in the context of HAART at Philp Moyo Clinic, Gauteng province

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DEDICATION

This research report is dedicated to my wife, Elizabeth and my daughters, Darik, my sons, Bennias and Jeriel for their inspiration, love and support, and to my Lord Jesus Christ for making everything possible.
DECLARATION

I Dr. MA Eyassu, hereby declare that the work, on which this thesis is based, is original (except where acknowledgments indicate otherwise) and that neither the whole work, nor any part of it, is to be, has been, or is being submitted for another degree of this or any other university.

Signed
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ACRONYMS AND ABBREVIATIONS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Anti-retroviral Therapy</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly Active Anti-Retroviral Therapy</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immune Deficiency Virus</td>
</tr>
<tr>
<td>NNRTI</td>
<td>Non-Nucleoside Reverse Transcriptase Inhibitor</td>
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<tr>
<td>NRTI</td>
<td>Nucleoside Reverse Transcriptase Inhibitor</td>
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<tr>
<td>PI</td>
<td>Protease inhibitor</td>
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<tr>
<td>PLHIV</td>
<td>People living with HIV</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>The Joint United Nations Program on HIV and AIDS</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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<td>WHO</td>
<td>World Health Organization</td>
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DEFINITION OF TERMS

Adherence: Adherence to ART is taking all ARV pills in the correctly prescribed doses at the right time and in the right way.

AIDS: this refers to a progressive immune deficiency caused by infection of CD4+ T cells with the human Immunodeficiency virus (HIV).

CD4+: this refers to an antigen maker of helper/inducer T cell that recognizes antigens.

Incidence: the number of new cases that occur during specific period of time in a population at risk for developing a disease.

Prevalence: this refers to the number of affected persons present in the population at specific time divided by the number of person in the population at the same time.

Viral load: levels of virus found in the blood per 10 millilitres (mls).
ABSTRACT

Background: With the introduction of ‘highly active antiretroviral therapy’ (HAART) HIV/AIDS has been transformed into a more manageable, chronic disease in our days. Despite the advent of effective antiretroviral therapy and its availability in many parts of the world, patients with HIV disease still present many palliative care challenges and problems. These patients continue to have a high burden of pain, other physical and psychological symptoms. The main role of palliative care is to minimize and prevent suffering and maximize physical function and quality of life in patients with serious illness such as HIV/AIDS.

AIM: To explore the palliative care needs of adult HIV patients at Philp Moyo clinic

Methods: This study utilized a quantitative cross sectional descriptive design which was carried out at Philp Moyo clinic, Ekurhuleni District, Gauteng province. Simple random sampling was used to recruit 162 adult participants. Data was collected using questionnaire by interviewers. Data was analyzed using STATA software version 13 and the analyzed data was presented by means of charts, graphs, and frequency tables.

Results. Detail assessment of each symptom at a point of interview using ESAS (0=best and 10=worst) indicated mean score of physical pain was (7), physical symptoms (6), emotional problems such as depression (6) and Anxiety (5) were noted. The prevalence of pain symptoms was the highest (90.7%) followed by depression (87.04%) and anxiety (80.86%). In this study only 30% of respondents were prescribed pain medications for 80% of participants’ pain was not treated appropriately.

Conclusion: The study showed there is high prevalence of pain and other symptoms indicating a high symptom burden experienced by the participants highlighted the needs of palliative care for ambulant patient population already receiving HAART. It is crucial to understand that palliative care approach is so important to address physical and psychological symptoms experienced by HIV patients
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CHAPTER 1: INTRODUCTION

Background

1.1 Epidemiology of HIV in South Africa

Like many countries in sub-Saharan Africa, HIV/AIDS is a major health problem in South Africa. The country has the highest prevalence of the HIV epidemic in the world.\(^1,2\)

The number of people living with HIV in the country during 2015 was estimated at 7 million.\(^3\) The HIV report for South Africa shows that there is an increasing mortality from HIV related illness. For example, during 2015 around 180,000 people were reported as having died from HIV related illness nationally\(^3,4\). Moreover, during 2015 there were 380,000 new HIV infections, clearly indicative of a country continuously facing HIV problems.\(^3,4\)

In developing the NSP for HIV 2017-2022, SANAC identified that more than 250,000 people died of HIV related illness. However, despite identifying this worrying mortality rate and representations from government and civil society for the inclusion of palliative care in the new NSP, the final document is silent on palliative care.\(^2\)

The antiretroviral treatment (ART) program in South Africa is well established and the largest on the globe. The finances have been mainly covered by the national Government and additional donor funding. Currently the country spends more than 1.5 billion US dollars annually to run the HIV and AIDS programs\(^2,3,4\). Despite all this effort, the prevalence of HIV is increasing (19.1 \%) in the country, although it varies markedly between regions\(^1,3\).

In accordance with the WHO recommended HIV guidelines (treatment for people with a CD4 count of less than 350) more than 3 million people received ART during 2015, which was above the universal access target (80 \%) of the country. However, in the revised 2013 HIV guidelines (CD4 less than 500) the coverage declined due to more people being eligible for ART. During 2016 ART coverage reached 48 \%.\(^5\)
The South African government implemented different strategies to improve levels of ART coverage, one of them was task shifting. Task shifting refers to the reallocation of tasks among available staff. In this case, lay counsellors (rather than nurses) carry out HIV tests, pharmacy assistants (rather than pharmacists) prescribe and nurses (rather than doctors) initiate ART. This reduces ‘bottlenecks’ in the healthcare system created by a staff shortage and increases the number of access points to treatment and good health care.²,⁴

Even though, the access to ART has improved significantly, many South Africans still start treatment late (when CD4 count is very low); they seek help only when they are sick and many are unaware of their HIV status until seriously ill.²,⁶ It is acknowledged that before 2009, the average CD4 count for starting ART in South Africa was just below 200. A study conducted in two Durban clinics found that 60 % of patients were tested when their CD4 counts dropped below 200⁷. From these patients, just 42 % were initiated with ART treatment within 12 months. Of those patients who were eligible for treatment, more than a fifth died, mostly before beginning treatment.⁷

In other cases, individuals simply refused treatment despite being eligible. A study in Soweto found that of 743 newly diagnosed HIV-positive adults eligible to begin treatment immediately, 20 % refused. More than a third gave “feeling healthy” as the reason for refusing treatment despite having a low CD4 count, with many also co-infected with tuberculosis¹,²

Despite all efforts, the rate of HIV infection remains high in Gauteng Province (HIV prevalence 17.8%) as in many parts of the country.²,³,⁴

1.2 Palliative care in HIV

The World Health Organization (WHO) defines palliative care as -

“an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems”⁸
Palliative care was developed initially to provide holistic care for cancer patients but is now recognized as appropriate care for people living with other life-threatening and life-limiting illnesses. The WHO emphasises the integration of palliative care as an essential component of HIV care from the initial part of diagnosis to the final stage of life.\textsuperscript{8,9}

The WHO recommends the importance of palliative care as a part of HIV management from the beginning of diagnosis (when the burden of pain and symptoms may be first experienced) to the end stage of life\textsuperscript{8,9} and includes bereavement care for the family. In addition, it is recognized that HIV is associated with refractory pain and other symptoms affecting the whole person, physical, psychological, social and spiritual.

The development of antiretroviral medication has dramatically changed the life of many patients by restoring their health and prolonging their life. However, as patients start to live longer, other challenges have occurred such as, treatment toxicities, drug resistance, increased co-morbidities and adherence related problems. In addition, the disease of HIV infection become a global threat particularly in low and middle income countries, where ART is limitedly available for patients who might be beneficial.\textsuperscript{10,11}

The roles of pain and symptom management, psychosocial and spiritual support for patient and the loved ones, and restoring of hope for a peaceful and dignified death remain vitally important for HIV patients as with cancer patients. Therefore, Palliative care plays a great role in addressing those types of problems in HIV patients.\textsuperscript{11}

HIV/AIDS is one of the most challenging problems for many people around the world. Globally, there are 34 million people estimated to be living with HIV. The magnitude of HIV is very high in Africa region accounting for 68 \% of the total global HIV burden.\textsuperscript{1} The disease is highly prevalent and disseminated in Africa but the accessibility and the coverage of HIV palliative care is largely absent.\textsuperscript{2,9,10} While there are prevalence studies of HIV-related pain and symptoms in economically
developed countries, there are few studies from Africa related to palliative care provision.

The United Nations Joint Program on AIDS (UNAIDS) has also recommended the importance of palliative care at the initial stage of HIV patients to improve quality of life.\(^9\)

In a systematic review of the evidence, HIV palliative care has been shown to be effective in the management of pain, symptoms and anxiety\(^10\). However, the available data were almost mainly established from developed countries \(^10, 11\). There is little literature considering appropriate palliative care needs assessment and outcomes in low income countries, that has hampered the development of appropriate clinical intervention, and health systems development\(^11, 12, 26\).

Although some data have been published on the needs and symptoms of the African HIV population and the evidence suggests a high burden of problems in the palliative phase, most of the affected population have been rarely investigated using well-validated outcome measures \(^11, 12, 13\).

The impact of ART in the management of HIV patients is so great in which people start to live longer, their lives having improved remarkably.\(^13\) As a result of the availability of ART, there is a significant reduction in mortality from HIV related illness. For example, in Africa (68 % of the global HIV-infected population) HIV-positive people have begun to enjoy the benefits of HAART. This results in a higher prevalence of HIV infection with more people requiring chronic care.\(^2, 3\)

In a comparison globally, the level of the HIV mortality rate in Africa remains high. In 2010, 1.2 million Africans died of HIV-related illness (representing 69 % of the global HIV related deaths)\(^2, 3, 4\). There are multiple causes related to the above problems but these are mainly because of poor resources.\(^3\)
The consequences of these challenges have had an effect both on health system problems, such as poor continuity of drug supply and patient issues such as default from HAART or non-adherence to HIV treatment.¹³

1.3 Palliative care in HIV in South Africa

The challenge and devastating effect of HIV/AIDS pushed the HIV/AIDS program to advance to a higher level. The government explored different approaches in its support for victims, such as the development of community-based models of palliative care¹.¹⁴ The National Department of Health (NDoH) recognizes the importance of a comprehensive range of care services in line with the goal of the National strategic plan (HIV/AIDS/STD).¹⁴

It also paid much attention to the need of community palliative care as part of primary health to deliver appropriate quality care.¹⁴,¹⁵ This is known as the integrated community palliative care (ICPC) approach which includes the family, and explores community resources particularly in limited resource settings.

The integrated community palliative model connects the health care services with different support groups within the community such as home-based care, hospice, NGOs and other support groups etc. which can potentially provide different levels of palliative care.¹⁴,¹⁵

Even though, the government recognizes the importance of providing care and support, there were no detail specific indicators contained in the strategic plan for such interventions in the past. Despite the importance of Palliative care in the management of HIV patients, neither is it given much attention nor included in the current National Strategic Plan which is of great concern in achieving quality of life. However, there is still a long way to go before the fact is acknowledged that people living with HIV need holistic care to enjoy quality of life.¹⁵,¹⁶

1.4 Pain management in HIV

It is very important to remember that the pain experienced by HIV patients is not just physical but also emotional social and spiritual; an approach introduced by Cecily Saunders known as “total pain”.¹⁷ The focus of this approach is to treat all
components of total pain. The main goal is to give maximum comfort to the patient by involving a multi-disciplinary team.

The contribution of HAART for HIV patents is most remarkable because it has helped them to live longer and to improve their quality of life. However, there are some challenges that cannot be overcome by medication alone but also requires the necessity of palliative care. During treatment, some patients developed virological failure, some experienced adverse effects from the medications, developing new co-morbidities and having their disease diagnosed late, all of which makes the management of HIV so complex.\textsuperscript{18,19}

It is very important to acknowledge that HIV patients may have different levels of pain throughout the course of the disease which can affect intensely their quality of life. Therefore, the holistic and comprehensive palliative care approaches are helpful for responding appropriately to various patient problems.

1.5 Study site

The study was conducted at the Phillip Moyo Community Health Centre, Etwatwa in the Eastern region of the Ekurhuleni health district. The Phillip Moyo CHC is the main CHC in Etwatwa, hence it serves patients from Etwatwa and its surrounding communities. There are three smaller clinics that refer patients to the Phillip Moyo CHC. According to Census 2011, the total population of Etwatwa was 124,435. The township is home to people with low levels of education and high unemployment. Most of the population is Black (99.7 \%) as per Census 2011. There are six units in the clinic that operates as a primary health care center namely, an obstetrical unit, a HIV clinic, a well-baby clinic, a dental clinic, and an allied unit. On the primary health care side approximately 80 to 120 patients were treated per day.

The CHC is staffed with professional and enrolled nurses, occupational therapists, social workers, a dentist, visiting podiatrist, dietician, clerical staff and one medical
officer when available as well as registrars who rotate through this facility at intervals.

There are no admission facilities or laboratory services both during and after working hours, hence patients are often stabilized clinically and transferred to other levels of care when necessary.

The hospitals attached to the clinic are Ruth First Hospital and the Tambo Memorial Hospital. The researcher has been involved in supervising the HIV program in the area.
CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter describes the reviewed literature relating to palliative care needs for HIV patients in the context of HAART. The researcher searched internet sources and library for articles relevant to his studies. The Data bases such as Pub Med, Cochrane library, and Google scholar were utilized on Palliative care need for patients on ART by using search terms, such as “Palliative care and HIV”. Relevant articles were selected and reviewed. Information obtained from several studies is presented below.

2.2 Why palliative care in HIV patients?

In separate studies, Wakeham, Merlin and Harding describe the role of palliative care in HIV as being very crucial for addressing multiple problems relating to illness, medications and development of complications (pain, adverse-effects, physical symptoms, emotional distress etc.)\textsuperscript{20,21,22}. Peltzer identifies that HIV patients experience a high degree of emotional problems such as anxiety, depression and other mental health problems that are remarkably higher than for the general population\textsuperscript{23}. In an American study conducted in Pennsylvania, Merlin found that not only psychological challenges were present among people living with HIV but also social and spiritual problems were common\textsuperscript{24}.

Although the introduction of ART enabled many countries to reduce the mortality rate of HIV related disease, the benefits of ART in some places are still unappreciated. Font \textit{et al} and Merlin \textit{et al} have pointed out that some of the reasons for the above facts are: limited adherence, socio-economic barriers, psychiatric illness, substance abuse, presence of co-morbidities, or resistant disease\textsuperscript{25,26}.

Despite the continuous efforts to increase ART access globally, it still remains a challenge in many places to get ART medication. It is so important to consider Palliative care in these contexts, and the possibility of integration into existing HIV care services.
In a systematic review Higgginson et al.\textsuperscript{26} identified definitions of needs assessment and approaches to assessing palliative care need. They analysed over 200 articles from various regions of the globe (Africa, Australia, Europe, USA, Latin America and USA).

They emphasised that before we conduct need assessment we should consider the definition of palliative care needs which may have different meaning for developed and developing countries. The definition of need from UK perspective is the ability to benefit from health care which is applicable to the palliative context “total wellbeing”. Whereas, this definition is problematic to less developed countries in which their condition is related with socio-economic problems, poor access to health care, different demographic and disease profiles.\textsuperscript{26}

Regarding the need assessment they found three categories namely comparative, corporate and epidemiological approaches.\textsuperscript{26}

1. Comparative need assessment compare and contrast services provided to the population from different areas.
2. Corporate need assessment is related directly to the receiving population to establish their needs and priorities
3. Epidemiological need assessment focuses on incidence and prevalence of symptoms, availability of health services and cost-effectiveness of potential services.

The benefits of palliative care

The advantage of palliative care is expedient to all groups of society (individual, family and community). Different studies by Merlin \textit{et al} and Sweeney \textit{et al} have indicated the great importance of palliative care on physical, emotional, social, and spiritual well-being, as well as cost implication.\textsuperscript{27,28}

Palliative care has shown great improvements in the quality of life through a variety of services offered in diverse settings in different nations both in developed and developing countries. Separate studies by Farinpoor \textit{et al} and Kalchman \textit{et al} have shown that there is a strong connection between the overall physical health of HIV
patients and their emotional, social, and spiritual well-being\textsuperscript{29,30}. An Ugandan study conducted by Apondi \textit{et al} on the effect of integration of CHBC program to outpatient clinic, found an improved social aspect of quality of life in HIV patients.\textsuperscript{31}

It has been noted that Palliative care services greatly improve outcomes for PLHIV on ART. In 2007 Malawian studies conducted by Zachariah \textit{et al}.\textsuperscript{32} and other studies conducted in several HIV care programmes in Africa and the Caribbean, found that there were much lower loss to follow-up rates among PLHIV enrolled in programmes that provided palliative care and ART compared with those that only provided clinic-based services. Moreover, the Malawian study clearly indicated a significantly lower mortality rate among PLHIV enrolled in the comprehensive programme. The study concluded that improved physical symptoms and emotional distress contributed to a lower adherence.\textsuperscript{32}

With regards to cost, it has been noted that the integration of palliative care at all levels of health services are generally cost effective. Different studies by Chandler \textit{et al}, Tramarin \textit{et al}, and Vys \textit{et al} have concurred that costs of care are significantly reduced by providing integrated palliative care and HIV care services. The evidence also shows that hospitalization is minimalized, improvements in utilization of healthcare services, reductions in hospitalization and enhanced quality of care.\textsuperscript{33,34,35}

\subsection*{2.3 Prevalence of Pain in HIV Infection}

Newshan \textit{et al} and Farrant \textit{et al}, in separate studies, found that people living with HIV experience different levels of pain causing illness, decreased quality of life and function\textsuperscript{36,37}. The source of this pain may occur from different causes such as, the infection itself, opportunistic infections, medication toxicities and malignancies.\textsuperscript{38,39}

The prevalence of pain among HIV patients varies from place to place but generally estimated from 40 \% to 60 \%.\textsuperscript{11} Even with the era of HIV treatment in developed countries like the United States of America (USA) the pain occurrence ranges from 39 \% to 55 \%.\textsuperscript{40}
Harding et al pointed out that the prevalence rate of pain in the developing world is difficult to estimate due to limited information. However, considering the facts related to the nature of the disease, the ART drugs side effects, and the limited availability of various types of analgesic drugs, they predicted that uncontrolled pain in HIV patients could be remarkably high.\textsuperscript{41}

A WHO report indicated that globally, the highest percentage (90\%) of the world’s morphine supply is utilized by developed nations as compared to a mere 10\% usage by developing nations where HIV prevalence is high.\textsuperscript{42}

In separate studies, Harding et al and Simms et al emphasized that pain control in HIV patients is vitally important and should always be considered for the duration of the illness. At the initial stage of HIV infection both treatments (ART and palliative care) should be combined. However, in the later phases, especially when the disease reaches the advanced stage, palliative care becomes the better option\textsuperscript{10,13}. In a systematic review Simms et al concluded that pain management for HIV patients is a global problem. It is a commonly neglected and undertreated symptom. Even in our age, where different HIV drugs are available, the pain symptom is still a great problem in HIV management.\textsuperscript{13,39} The expectation of pain control in developed countries are supposed to be better, however, the study shows that many HIV patients (60-85\%) do not have appropriate pain management. \textsuperscript{41,42,43}

In different studies Simms and Harding pointed out that ART with palliative and disease-modifying measures will enhance upon improved pain control in complicated HIV/AIDS patients. Some ART drugs associated with neuropathic pain (certain nucleoside reverse transcriptase inhibitors such as didanosine, stavudine, and to a lesser extent, zidovudine).\textsuperscript{10,13} This type of pain can be reduced by reducing the dose of stavudine or by changing to another group of drugs that have less neurotoxic effects.\textsuperscript{13}

The cause of physical pain in HIV patients is multifactorial and mainly associated with:
1. Disease progression\textsuperscript{44} as described by Frich & Borgbjerg in their longitudinal study.

2. Opportunistic infections\textsuperscript{45,46} as indicated by (Selwyn et al and Tsao et al).

3. Adverse effects of ART medications\textsuperscript{44,45,46}

4. Effects of non-specific chronic debilitating diseases (diabetic neuropathy).\textsuperscript{45,46}

2.4 Pain Assessment and Management

The assessment or measurement of pain in HIV patients like chronic diseases should be regularly considered during the follow-up of the patients. Breitbart indicated that the first approach should be assessment of pain etiology and contributing factors.\textsuperscript{47}

There are different tools to assess the pain scales that include: Pain Faces Scale, Verbal Rating Scale, Visual Analogue Scale, Numeric Pain Intensity Scale etc. The WHO Pain guidelines for HIV patients is similar to that of cancer; so, the choice of analgesic agents should follow the WHO pain ladder:\textsuperscript{48}

1. Step one, non-opioid analgesics: these analgesics include (paracetamol, non-steroidal anti-inflammatory drugs (NSAIDs), and salicylates).

2. Second step, opioid for mild to moderate pain: naïve patients inexperienced with opiates can be treated with (weak opioids such as tramadol)

3. Third step, opioid for moderate to severe pain: opioid non-naïve or seasoned patients with severe pain are treated with strong opioids (e.g., morphine, methadone, and fentanyl).

Basu et al\textsuperscript{49} in their research pointed out that the approach to pain management in HIV patients with a history of drug abuse is slightly different than the non-abuser. In case of acute pain, those patients need to be treated with short-acting opioids and
easily monitored, titrated and decreased once pain is controlled or toxicity occurs. The study further indicated that these drugs do not cause or enhance dependency\textsuperscript{49}.

2.5 Physical Symptoms

In a systematic review conducted by Simms \textit{et al} and in a separate study conducted by Norval, it was described that HIV infection is associated with a wide spectrum of symptoms and that this may occur as a result of HIV infection or other opportunistic diseases as well as the side effects of the ART and malignancy\textsuperscript{13,18}. In separate studies, Farrant and Harding identified that the most common distressing symptoms in HIV patients include weight loss and other physical symptoms (anorexia, nausea, vomiting, fatigue, anxiety, depression, cough, fever, and dyspnoea)\textsuperscript{36,40}. The treatment of the underlying cause is important to bring relief from symptoms or discomfort.

The prevalence of symptoms other than pain is a common problem among people with HIV. In people who are symptomatic or have AIDS, the following symptoms are particularly prevalent: anorexia (63%) fatigue (60–71%) fever (48%) insomnia (51–55%) skin problems (34–72%) and cough (37–58%). However, symptoms and medication-related side effects are also common among PWLHIV on ART\textsuperscript{37,41}. The presence of symptoms and side effects have also been documented as a barrier to ART adherence in a growing number of studies. Addressing these symptoms can enhance treatment adherence and quality of life. Psychological distress is also another common condition in HIV patients. A study by Merlin \textit{et al} indicated that HIV positive patients in developed countries such as the USA are three times more likely to have psychiatric illness than HIV-negative patients. It also shows furthermore, 38 to 75% of HIV patients will experience some psychiatric condition during the illness\textsuperscript{24}.

2.6 Communication

Good communication is an important component of palliative care which strengthens the patient-health provider relationship. There are numerous challenges that health workers need to consider, these include being the bearers of bad news and building
hope, discussing treatment options, prognosis and advance care planning. Harding and Simms, in separate studies, recommended that it is quite essential to consider detailed discussion with the patient bearing in mind the above mentioned points starting at the initial stages of the disease.\textsuperscript{10,13}

It is common practice in many developed countries that clinicians play a great role in establishing a power of attorney for their patients. Although the decision of some patients could be altered during the course of their illness, it is still vitally important to initiate the discussion. HIV patients, as with other patients, may resist talking about end-of-life issues.\textsuperscript{50} Therefore, it is important to focus on the current situation and if the illness progresses, the end-of-life discussion can be reconsidered.

Some studies argue that the level of CD4 count and viral load may not be a true reflection of the prognosis of advanced HIV infection, further complicating end-of-life discussions and decision making\textsuperscript{38,50}. Measures of functional status, such as the Karnofsky score and the Palliative Performance Scale may play an important role in assessing total functionality\textsuperscript{40,42} and disease progression.

### 2.7 Psychosocial and Spiritual Support

A study by Selman \textit{et al} pointed out that psychosocial and spiritual support are the main components of palliative care which should not be ignored in the management of HIV infected patients.\textsuperscript{51} A multi-disciplinary palliative care team is necessary to address various patient concerns throughout the course of illness. Addressing emotional, social, and physical problems is impossible for a single provider; rather, it takes health workers to work together as a team\textsuperscript{51}.

Many studies have indicated that HIV patients encounter emotional and spiritual problems. For example, a Tanzanian study conducted by Antelman \textit{et al} indicated that among newly diagnosed, asymptomatic women 57\% were found to have symptoms of depression\textsuperscript{52}. Moreover, in another study by Green \textit{et al} conducted in Vietnam, 82 \% of HIV patients experience emotional breakdown or are joyless most of the time.\textsuperscript{53}
The other component of quality of life that needs to be considered in pain management is the spiritual well-being of the patient. McClain et al identified in their study that there is a link between low-level scores in spiritual well-being (lack of peace, feeling that one’s life is meaningless or purposeless) and suicidal thoughts. In this situation, it is crucial to have a multidisciplinary team helping the patient and the patient’s family. During this difficult time, most patients and their loved ones are exposed to emotional distress. It is quite important to provide patients and their families with continuous comfort or counselling. As emphasized strongly by Brecht et al psychosocial support does not cease at the patient’s death. The palliative care team continues caring for survivors and provides bereavement support.

2.8 Palliative Care Needs of HIV Patients on ART

Beyond a doubt palliative care is essential for people living with HIV. As demonstrated by several studies, HIV patients on ART still experience different forms of suffering.

In a Tanzanian study conducted by Harding and Collins found that out of 434 patients put on ART 53 % were identified as having palliative care needs. They concluded that Palliative care continues to be an important part of HIV programs even in the presence of ARV treatment.

Separate studies from around the world conducted by Harding et al, Newshan et al, and Brecht et al indicate that although ART helps to improve the general physical status of the HIV patients it has limited effect on psychosocial well-being and in some cases even leads to a reduced quality of life. This is because HIV patients on ART may have several psychological, social, and spiritual problems while on ART. In addition, Harding et al describe depression and lack of social support as being associated with lack of adherence to ART.

There are various reasons that make palliative care so vital for PLHIV on ART. One of the reasons is that if ART initiated late, it may cause patients to develop physical problems or experience multiple, distressing side effects such as immune reconstitution inflammatory syndrome as described by Harding et al. Some
patients may have associated chronic pain due to previous illness and comorbidities.\textsuperscript{56}

2.9 Pain and Symptoms Assessment Tools

The African Palliative Care Association (APCA) African Palliative Outcome Scale (POS) was used to measure the 3-day period prevalence and associated burden of multidimensional problems. It contains 10 items and aims to address the physical and psychological symptoms, spiritual practical and emotional concerns and the psychological needs of the patient and the family. Questions 1-7 are linked to the patient whereas questions 8-10 are directed at family or care givers. This tool was developed across eight sub-Saharan African countries and validated among 682 patients and 437 caregivers.\textsuperscript{57,58} Each item is scored on a scale of 0–5. A stable three factor structure has been identified for patient items, each with good internal consistency.

The Edmonton Symptom Assessment Scale (ESAS) is simple and easy to use with cancer patients. Bruera et al described it as a simple tool designed to assist in the assessment of nine symptoms common in cancer patients which include pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. Each symptom is rated on a scale from zero to ten; zero meaning the symptom is absent and ten indicating the worst possible severity. It is based on the subjective report of the patient. Moreover, it is very simple and helpful for holistic clinical assessment.\textsuperscript{59} The ESAS is a validated tool for use with patients in the medical oncology group. Moreover, the ESAS primarily evaluates physical wellness. This tool can also be used for evaluation of symptoms of other medical conditions.

The Pain Management Index (PMI) is one of the tools used to measure adequacy of analgesic use in cancer and other chronic pain conditions. Based on the WHO pain ladder, the PMI is helpful in assessing pain control by means of comparison of the most potent analgesic used by a patient relative to the level of his/her pain.\textsuperscript{5,60}
The items below have been identified from the literature; and the definitions which have been applied to this study are as follows -

**Pain:** the definition of pain in palliative care is what the patient describes as discomfit/soreness or suffering\(^6^1\)

**Symptoms:** representing physical problems from a patient-centered perspective. Self-reported symptoms have been shown to be more complete and relevant clinically than problems reported by health providers\(^6^2\)

**Worry:** representing psychological problems. Worry is a symptom of all anxiety disorders and is frequently associated with depression\(^6^3\)

**Well-being:** representing quality of life and the will to live\(^6^7\)

**Support:** The family and their care givers are important aspects of palliative care. Social support in the literature is divided into two concepts: emotional and informational support\(^6^4\)

**Peace:** the question, “Are you at peace?” is a measure of spiritual well-being that has been validated independently in palliative care population in Uganda, South Africa and the USA\(^6^5\)

**Information:** representing the informational and tangible as being distinct from emotional support\(^6^6,6^7\)

**Problem Statement**

Chronic patients particularly HIV/AIDS patients have complex issues relating to physical pain and symptoms as well as psychosocial and spiritual problems. The WHO has recommended that the integration of palliative care in HIV/AIDS
management is essential throughout the course of illness to achieve better outcomes and a better quality of life.\textsuperscript{1,2}

Although the role of ART on the management of the HIV patient is remarkable, still the adherence issue is a great concern.\textsuperscript{59} The integration of palliative care plays a great role in the outcome of patient management. Holistic management including palliative care enables quality health improvement and long life for HIV/AIDS patients.

There are a few studies that explain the need of palliative care for HIV patients in hospital settings in South Africa but there is no study that shows the need at the clinic level. This study was conducted to evaluate palliative care needs for HIV patients at the clinic level. Therefore, this research might be useful for policy makers and for further research. Also, it might be useful in enlightening the knowledge and understanding of healthcare professionals regarding palliative care and appropriate pain management for HIV and AIDS patients within the district.

**Aims and Objectives**

**AIM:** To explore the palliative care need in adult HIV patients at Philp Moyo Clinic

**Objectives:**

1. To describe socio-demographic characteristics of adult HIV/AIDS patients who participated in the study.
2. To investigate the prevalence of HIV associated symptoms among adult HIV patients in the clinic.
3. To assess the appropriate pain management of adult HIV patients in the clinic.
CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

This chapter explains the methodology that was used in study. Furthermore, the chapter looks at the study site, study design, target and study populations, sampling techniques, research instruments, ethical considerations, data collection, data quality control, as well as data management and analysis.

3.2 Study Design

A cross-sectional descriptive design was used in this study.

3.3 Study Site

The study was conducted at the Phillip Moyo Community Health Centre, Etwatwa which is located on the Eastern region of the Ekurhuleni health district. Philip Moyo CHC is the main CHC in Etwatwa and it serves patients from Etwatwa and its surrounding communities.

3.4 Study Population

The study population consisted of all adult HIV patients older than 18 years who were attending the Philip Moyo clinic.

3.5 Selection Criteria

Inclusion criteria

- Adult patients who were 18 years and older with confirmed HIV diagnosis attending the Philip Moyo Clinic and who were put on HAART.
- The other requirement was that the participants should be physically and mentally competent to participate in the interview. They were screened and clinically assessed (general medical examination and mental assessment using mini mental assessment tools by the clinic nurses before the interview).
Exclusion criteria
Those patients younger than 18 years old were not included in the study. HIV positive patients ineligible for HAART were excluded.

3.6 Sample Size and Sampling
3.6.1 Sample size
The sample was determined by Kothari’s formula as follows\textsuperscript{67}:

\[
n = \frac{z_{\alpha/2}^2 \times p \times q}{e^2}
\]

where \( z_{\alpha/2} \) is the \( z \) value from the standard normal distribution table corresponding to \((1 - \alpha)\% \) confidence level and \( \alpha \) is level of significance, \( p \) is the proportion of HIV and AIDS patients, \( q = 1 - p \) and \( e \) is an acceptable error margin (precision of measurement). Estimates of average rates of HIV infection in South Africa during 2014 was 12\% \textsuperscript{3,10}. Using the upper range for non-adherence, 95\% level of significance and 5\% error margin, the sample size for this study is approximately

\[
n = \frac{z_{\alpha/2}^2 \times p \times q}{e^2} = \frac{1.96^2 \times 0.12 \times 0.88}{0.05^2} \approx 162
\]

3.6.2 Sampling methods
The random systematic sampling technique was applied to the selection of the participants; every 3\textsuperscript{rd} patient selected from the appointment register until the required sample size was obtained.

3.7 Data Collection Tools
With respect to data collection tools, five sections were used to collect the relevant information: 1) Demographic 2) APCA African POS 3) ESAS 4) ECOG and 5) Appropriateness of pain management. The details of each part are discussed below.

The questionnaire was designed to cover demographic parameters. The following patient demographical and clinical data were collected: age, gender, household size,
number of dependent children, residential area, family type, employment and income
primary diagnosis and primary place of palliative care (home, inpatient, outpatient,
day care).

Data for this study were collected using internationally validated tools: the African
Palliative Care Association (APCA) African Palliative Outcome Scale (POS) and The
Edmonton Symptom Assessment Scale (ESAS)\textsuperscript{58}.

Functional status was measured using the Eastern Cooperative Oncology Group, a
validated measure of physical function.

The appropriateness of pain management was also assessed using the WHO pain
ladder and Pain Management Index (PMI). The PMI methods as described by
Russell \textit{et al} are used to evaluate the adequacy of pain management in cancer
patients.\textsuperscript{60}

The PMI tools assess the pain management rated on four scales which are as
follows: “0” no analgesia, “1” non-opioid analgesia, “2” weak opioid and “3” strong
opioid. The PMI is calculated by subtracting the POS pain score from the analgesic
treatment level, which results in a score value ranging from -3 (severe pain in a
patient on no analgesia) to a value of 0 (appropriate pain management). A matter of
concern would be a positive score indicating over treatment such as a patient with no
pain on strong opioids. The interpretation of this result is that negative scores are
considered as inadequate pain treatment whereas positive or zero scores are
described as acceptable pain management.

\subsection*{3.8 Data Collection Process}

\subsubsection*{3.8.1 Recruitment assistance}

Two nurses were recruited from the wellness clinic at Philip Moyo CHC to help with
the collection of data using the data capture sheet. They received training on the
research project and research ethics.
3.8.2 Introduction of the study to the study site

Information about the research was given to clinic staff members by the researcher during a staff meeting, with the permission of the facility manager. A one-hour discussion was arranged at the clinic, two weeks before the date of data collection. The discussion included: the support of staff members who would be identifying appropriate patients, ensuring that patients interviewed were seen by the former as soon as they had completed the research interview, and the provision of a private room where the interview was to be conducted.

3.8.3 Recruitment of participants

In the clinic, ± 100 patients were seen per day and ± 50 patients were started on ART every working day, except Friday which was reserved for administration. Participants were selected randomly (every 3rd patient from the patient register book for the day) by research assistants while patients were waiting to be seen by the clinic doctors. Up to 15 participants per day were recruited until the required number of 162 was met. All the information was written in the language that was well understood by participants. The research assistants explained the research study to potential participants: that the interview would be conducted on an individual basis and not as a group, that they would be given an opportunity to ask questions, and were informed that they had the right to withdraw from participating at any time during the time of data collection. Written informed consent was obtained voluntarily from the participants by interviewers before starting data collection.

3.8.4 Data collection methods

The interview was conducted by the research assistants using the data capture sheet and took place in a private room. Individual participants were interviewed for a maximum duration of 30 minutes or less. Additional information was also collected by the research assistants from patients’ records following the consent of the latter. The dignity of respondents was maintained by the researcher during the study. During data collection, the privacy of respondents was maintained by allowing them to respond to the questionnaire in the private rooms.
3.9 Data Storage and Confidentiality

Neither their names nor any information that could identify them appeared in the questionnaire. Respondents were notified that no names were used in files, but codes were allocated to each participant. The master copy of names and codes was secured in a separate secure file. The data were placed in a safe place.

Data were stored on the researcher’s computer and secured with a password. The hard copy was placed in a locked file. The master copy was also kept separately to protect patient identity.

3.10 Data Analysis

Data were entered on a computer using Microsoft Excel Office and STATA version 13 by the researcher after developing data capturing codes. Then data were analysed using STATA Software by the researcher, assisted by the statistician. Various types of descriptive statistics (such as frequency tables, graphs / charts and summary measures were used to explore the data collected. Descriptive and inferential statistical tests were applied.

Logistic regression was applied to assess the level of interaction between the independent variables and the dependent variables. The independent variables are the socio-demographic factors and other clinical factors which are mentioned in this study. Regarding the dependent variables, there are seven items from APCA African POS (pain, physical symptoms and psychological distress) assessed separately. The outcomes of the analysis are presented in a table form. The first three items namely pain, symptoms other than pain, and worry were scored from 0-5 i.e. best to worst. For example, no pain (0) and worst pain (5). The following four items were scored from 0-5 i.e. worst to best in terms of ability to share. For example, (0) unable to share and (5) able to share freely (ability to share feelings, life worthwhile, at peace, enough information - best score is 5)
3.11 Ethical Considerations

3.11.1 Permission to conduct the Research

Ethical approval was obtained from the Human Research Ethics Committee, University of Cape Town (UCT). Written permission to start the study was also received from the Ekurhuleni District Health Ethics Committee (mandated to give authorization to conduct the study on the site). Verbal permission from facility manager was also granted.

3.12 Vulnerable Participants

The PI and research assistants were mindful of; the fact that HIV patients have vulnerabilities, the power differential between researcher and participant, as well as that between clinician and patient. Care was taken to ensure potential participants were not unduly influenced to partake in the research.

The researcher protected the respondents from any form of harm and discomfort during the process of data collection. The researcher took into consideration the participants at all times and explained to them that they were free to withdraw from the study if they wished to stop at any time during the process, without a negative effect on their care.
CHAPTER 4: RESEARCH RESULTS

4.1 Introduction

This chapter presents the findings of this study based on the data analysis by using the STATA version 13 program. Furthermore, the chapter includes the following results: socio-demographic characteristics, data on HIV associated symptoms and appropriateness of pain management, in adult HIV/AIDS patients. The results are presented in three main sections.

4.2 Socio-Demographic Characteristics

**Table 4.1 Demographic Characteristics of participants at PMC**

<table>
<thead>
<tr>
<th>Age</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>10</td>
<td>6.18 %</td>
</tr>
<tr>
<td>25-34</td>
<td>65</td>
<td>40.13 %</td>
</tr>
<tr>
<td>35-44</td>
<td>50</td>
<td>29.63 %</td>
</tr>
<tr>
<td>45-54</td>
<td>27</td>
<td>16.66 %</td>
</tr>
<tr>
<td>55-64</td>
<td>7</td>
<td>4.32 %</td>
</tr>
<tr>
<td>65 and older</td>
<td>3</td>
<td>3.08 %</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>117</td>
<td>72.22 %</td>
</tr>
<tr>
<td>Male</td>
<td>45</td>
<td>27.78 %</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>85</td>
<td>52.47 %</td>
</tr>
<tr>
<td>Married</td>
<td>29</td>
<td>17.90 %</td>
</tr>
<tr>
<td>Cohabitng</td>
<td>29</td>
<td>17.9.0 %</td>
</tr>
<tr>
<td>Others</td>
<td>19</td>
<td>11.73 %</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No (formal) education</td>
<td>19</td>
<td>11.73 %</td>
</tr>
<tr>
<td>Primary</td>
<td>25</td>
<td>15.43 %</td>
</tr>
<tr>
<td>Secondary</td>
<td>111</td>
<td>68.52 %</td>
</tr>
</tbody>
</table>
### 4.2.1 Age of respondents

The mean age was 38 years with a standard deviation of 10.39 and ages ranged from a minimum of 18 years to a maximum of 68 years. Most of the respondents fell in the age group of 25-34 (40.13 %), followed by the age group categories of 35-44 and 45-54 accounting for 29.63 % and 16.66 % respectively. All detailed information on the age categories of respondents are described in Table 4.1.

### 4.2.2. Gender of respondents

With respect to the gender distribution, the majority of the respondents (72.22 %) in this study were female and their male counterparts comprised 27.78 % of the sample.

### 4.2.3. Marital status of the respondents

Regarding their marital status, the majority of participants were single (52.4 %), the married participants and those cohabiting were equally accounted (17.9 %) respectively and the other participants i.e. widowed, divorced (11 %).

### 4.2.4 Level of education attained by respondents

The percentage distribution of educational status of the respondents is illustrated in Table 4.1 Most them had completed secondary school (68.52 %) followed by those who had; primary school education (15.43 %), no formal education (11.73 %), and tertiary education (4.8%).

<table>
<thead>
<tr>
<th>House members</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children</td>
<td>69</td>
<td>42.59 %</td>
</tr>
<tr>
<td>Adult without earning</td>
<td>60</td>
<td>37.04 %</td>
</tr>
<tr>
<td>Adult with earning</td>
<td>33</td>
<td>20.37 %</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment Frequency Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
</tr>
<tr>
<td>Unemployed</td>
</tr>
</tbody>
</table>

| Tertiary | 7 | 4.32 % |

---

Tertiary
4.2.5. Employment status of respondents

As indicated in Table 4.1, the percentage of unemployed respondents (59.26 %) was very high in comparison with the employed respondents (40.74 %).

4.2.6 Households members of the respondents

The mean average of the total house numbers was 4 with a standard deviation of 1.41. Further exploration of the distribution showed that over 70 % of the house members were children and adults without any income earnings.

4.3 Clinical Information

4.3.1 The level of CD4 count of the respondents

As described below in Table 4.2, the majority of the participants (57.41 %) had their CD4 level between “200-500” followed by those participants (19.75 %) with a CD4 count above “500”. Almost a quarter of the participants had their CD4 level below “200”.

<table>
<thead>
<tr>
<th>CD4 level</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;100</td>
<td>16</td>
<td>9.88 %</td>
</tr>
<tr>
<td>100-200</td>
<td>21</td>
<td>12.96 %</td>
</tr>
<tr>
<td>200-500</td>
<td>93</td>
<td>57.41 %</td>
</tr>
<tr>
<td>&gt;500</td>
<td>32</td>
<td>19.75 %</td>
</tr>
<tr>
<td>Total</td>
<td>162</td>
<td>100 %</td>
</tr>
</tbody>
</table>

Table 4.2: CD4 level of the respondents at the Philip Moyo Clinic
4.4 Pain and Symptoms Assessment Using Tools of (APCA)

The characteristics of respondents regarding pain, physical symptoms, psychological and spiritual factors are shown in Table 4.3.

<table>
<thead>
<tr>
<th>POS patient items</th>
<th>Mean</th>
<th>Median</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>3</td>
<td>3</td>
<td>1.26</td>
</tr>
<tr>
<td>Symptoms</td>
<td>3</td>
<td>3</td>
<td>1.43</td>
</tr>
<tr>
<td>Worry</td>
<td>3</td>
<td>3</td>
<td>1.42</td>
</tr>
<tr>
<td>Sharing feelings</td>
<td>2</td>
<td>2</td>
<td>1.80</td>
</tr>
<tr>
<td>Life worth while</td>
<td>3</td>
<td>4</td>
<td>1.76</td>
</tr>
<tr>
<td>At peace</td>
<td>3</td>
<td>3</td>
<td>1.86</td>
</tr>
<tr>
<td>Information to plan</td>
<td>2</td>
<td>3</td>
<td>0.94</td>
</tr>
</tbody>
</table>

4.5 Symptoms Assessment with ESAS

The symptoms assessment of the respondents using ESAS tools indicated that the majority of the respondents (90.74 %) presented with pain symptoms followed by depression (87.04 %) and anxiety (80.86 %). The remaining presentations of symptoms are described below.

Further analysis of the mean score of each symptom is described below, of which the highest was pain symptoms (7) followed by depression (6) and anxiety (5). Details of the findings are presented in Table 4.4.
Table 4.4 Edmonton Symptom Assessment System: 0 (best) – 10 (worst)

<table>
<thead>
<tr>
<th>ESAS patient items</th>
<th>Prevalence</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>90.74 %</td>
<td>7</td>
<td>2.40</td>
</tr>
<tr>
<td>Depression</td>
<td>87.04 %</td>
<td>6</td>
<td>2.43</td>
</tr>
<tr>
<td>Anxiety</td>
<td>80.86 %</td>
<td>5</td>
<td>2.68</td>
</tr>
<tr>
<td>Well-being</td>
<td>77.78 %</td>
<td>4</td>
<td>2.25</td>
</tr>
<tr>
<td>Tiredness</td>
<td>74.69 %</td>
<td>4</td>
<td>2.81</td>
</tr>
<tr>
<td>Difficulty in Breathing</td>
<td>64.20 %</td>
<td>3</td>
<td>2.74</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>59.26 %</td>
<td>3</td>
<td>2.77</td>
</tr>
<tr>
<td>Lack of appetite</td>
<td>58.25 %</td>
<td>3</td>
<td>1.89</td>
</tr>
<tr>
<td>Nausea</td>
<td>25.31 %</td>
<td>1</td>
<td>1.74</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>87.65 %</td>
<td>5</td>
<td>1.99</td>
</tr>
</tbody>
</table>

4.6 Severity of Pain

Regarding the severity of pain, the majority of participants (70.99 %) had moderate pain and the rest of the percentages of distribution on kinds of pain are shown in Table 4.5. below.

Table 4.5: Percentage distribution of severity of pain

<table>
<thead>
<tr>
<th>Severity of pain</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td>26</td>
<td>16.05 %</td>
</tr>
<tr>
<td>Mild pain</td>
<td>10</td>
<td>6.17 %</td>
</tr>
<tr>
<td>Moderate pain</td>
<td>115</td>
<td>70.99 %</td>
</tr>
<tr>
<td>Severe pain</td>
<td>11</td>
<td>6.79 %</td>
</tr>
<tr>
<td>Total</td>
<td>162</td>
<td>100 %</td>
</tr>
</tbody>
</table>
4.7 Analgesic Prescriptions for the Respondents

Most of the respondents (71 %) were not given any analgesic medication but it was prescribed for the rest of them (29 %).

Figure 4.1: Respondent’s prescription for analgesia at the Philip Moyo Clinic

The kinds of analgesic drugs which were used are presented in Table 4.6.

Table 4.6: Percentage distribution of prescribed analgesia

<table>
<thead>
<tr>
<th>Type of Analgesia</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>115</td>
<td>70.99 %</td>
</tr>
<tr>
<td>NSAID/Panado</td>
<td>38</td>
<td>23.46 %</td>
</tr>
<tr>
<td>Weak opioids</td>
<td>7</td>
<td>4.32 %</td>
</tr>
<tr>
<td>Strong opioids</td>
<td>2</td>
<td>1.23 %</td>
</tr>
<tr>
<td>Total</td>
<td>162</td>
<td>100 %</td>
</tr>
</tbody>
</table>
Regarding the kinds of analgesic drugs used by the respondents; around 24 % were simple analgesia such as NSAID or Panado (step 1 analgesia), the other 4 % weak opioids (step 2 analgesia) and only 1.23 % strong opioids (step 3 analgesia).

4.8 Appropriateness of Pain Management

Using the WHO step ladder pain management tools and Pain Management Index (PMI) the appropriateness of pain management was assessed and the findings indicated that 80 % of respondents were inappropriately managed (Table 4.7).

PMI percentage Distribution

<table>
<thead>
<tr>
<th>Score</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>2</td>
<td>1.23 %</td>
</tr>
<tr>
<td>-2</td>
<td>80</td>
<td>49.38 %</td>
</tr>
<tr>
<td>-1</td>
<td>49</td>
<td>30.25 %</td>
</tr>
<tr>
<td>0</td>
<td>31</td>
<td>19.14 %</td>
</tr>
<tr>
<td>Total</td>
<td>162</td>
<td>100 %</td>
</tr>
</tbody>
</table>

Further details of PMI scores against corresponding kinds of severity of pain cross are tabulated below (Table 4.8)
Table 4.8: PMI with correspondence kinds of pain

<table>
<thead>
<tr>
<th>PMI scores</th>
<th>No pain</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>-2</td>
<td>0</td>
<td>0</td>
<td>77</td>
<td>3</td>
<td>80</td>
</tr>
<tr>
<td>-1</td>
<td>0</td>
<td>10</td>
<td>35</td>
<td>4</td>
<td>49</td>
</tr>
<tr>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>31</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
<td>10</td>
<td>115</td>
<td>11</td>
<td>162</td>
</tr>
</tbody>
</table>

4.9 ECOG Functional Assessment

Regarding the functional status of the respondents, an overwhelming majority (96.3 %) were physically fully active. The rest of the findings are described in Table 4.9

Table 4.9: Distribution of respondents according to ECOG assessment at the Philip Moyo Clinic

<table>
<thead>
<tr>
<th>ECOG</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fully active</td>
<td>156</td>
<td>96.3 %</td>
</tr>
<tr>
<td>Restricted</td>
<td>2</td>
<td>1.23 %</td>
</tr>
<tr>
<td>Ambulatory</td>
<td>2</td>
<td>1.23 %</td>
</tr>
<tr>
<td>Limited self-care</td>
<td>1</td>
<td>0.62 %</td>
</tr>
<tr>
<td>Fully disabled</td>
<td>1</td>
<td>0.62 %</td>
</tr>
<tr>
<td>Total</td>
<td>162</td>
<td>100 %</td>
</tr>
</tbody>
</table>

4.10 Logistic Regression Analysis of POS and Socio-Demographic Factors

Logistic analysis of socio-demographic and clinical factors with dependent variables POS (pain, other physical symptoms and psychological symptoms).
### Table 4.10: Logistic regressions output of POS

<table>
<thead>
<tr>
<th>Severity of pain</th>
<th>Odds Ratio</th>
<th>Standard Error</th>
<th>Z</th>
<th>P-value</th>
<th>C I 95 %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>.81</td>
<td>.44</td>
<td>-0.39</td>
<td>0.69</td>
<td>.28 - 2.34</td>
</tr>
<tr>
<td>Age</td>
<td>1.02</td>
<td>.03</td>
<td>0.90</td>
<td>0.37</td>
<td>.97 - 1.08</td>
</tr>
<tr>
<td>Marital (status)</td>
<td>1.23</td>
<td>.17</td>
<td>1.45</td>
<td>0.15</td>
<td>.93 - 1.62</td>
</tr>
<tr>
<td>Household</td>
<td>1.04</td>
<td>.17</td>
<td>0.23</td>
<td>0.82</td>
<td>.75 - 1.44</td>
</tr>
<tr>
<td>Household MM</td>
<td>.81</td>
<td>.24</td>
<td>-0.72</td>
<td>0.47</td>
<td>.45 - 1.45</td>
</tr>
<tr>
<td>Employment</td>
<td>.99</td>
<td>.16</td>
<td>-0.08</td>
<td>0.94</td>
<td>.71 - 1.37</td>
</tr>
<tr>
<td>Education</td>
<td>1.58</td>
<td>.52</td>
<td>1.41</td>
<td>0.16</td>
<td>.83 - 2.99</td>
</tr>
<tr>
<td>CD4</td>
<td>.43</td>
<td>.15</td>
<td>-2.38</td>
<td>0.02</td>
<td>.22 - .86</td>
</tr>
<tr>
<td>ECOG</td>
<td>1.81</td>
<td>.15</td>
<td>0.51</td>
<td>0.61</td>
<td>.18 - 17.76</td>
</tr>
<tr>
<td>_cons</td>
<td>5.66</td>
<td>13.39</td>
<td>0.73</td>
<td>0.46</td>
<td>.05 - 585.17</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Psychological Symptoms</th>
<th>Odds Ratio</th>
<th>Standard Error</th>
<th>Z</th>
<th>P-value</th>
<th>C I 95 %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>1.90</td>
<td>.75</td>
<td>1.63</td>
<td>0.10</td>
<td>.88 - 4.11</td>
</tr>
<tr>
<td>Age</td>
<td>.99</td>
<td>.02</td>
<td>-0.43</td>
<td>0.67</td>
<td>.96 - 1.03</td>
</tr>
<tr>
<td>Marital</td>
<td>1.00</td>
<td>.09</td>
<td>0.01</td>
<td>0.99</td>
<td>.83 - 1.20</td>
</tr>
<tr>
<td>Household</td>
<td>1.08</td>
<td>.14</td>
<td>0.61</td>
<td>0.54</td>
<td>.84 - 1.39</td>
</tr>
<tr>
<td>Household MM</td>
<td>1.40</td>
<td>.33</td>
<td>1.43</td>
<td>0.15</td>
<td>.88 - 2.22</td>
</tr>
<tr>
<td>Employment</td>
<td>.97</td>
<td>.13</td>
<td>-0.22</td>
<td>0.82</td>
<td>.75 - 1.25</td>
</tr>
<tr>
<td>Education</td>
<td>.51</td>
<td>.15</td>
<td>-2.24</td>
<td>0.02</td>
<td>.29 - .92</td>
</tr>
<tr>
<td>CD4</td>
<td>.88</td>
<td>.21</td>
<td>-0.56</td>
<td>0.57</td>
<td>.55 - 1.39</td>
</tr>
<tr>
<td>ECOG</td>
<td>1.74</td>
<td>.98</td>
<td>0.98</td>
<td>0.33</td>
<td>.57 - 5.26</td>
</tr>
<tr>
<td>_cons</td>
<td>2.07</td>
<td>3.39</td>
<td>0.44</td>
<td>0.66</td>
<td>.08 - 51.25</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other physical symptoms</th>
<th>Odds Ratio</th>
<th>Standard Error</th>
<th>Z</th>
<th>P-value</th>
<th>C I 95 %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>1.74</td>
<td>.71</td>
<td>1.36</td>
<td>0.17</td>
<td>.78 - 3.87</td>
</tr>
<tr>
<td>Age</td>
<td>1.04</td>
<td>.02</td>
<td>2.15</td>
<td>0.03</td>
<td>1.00 - 1.08</td>
</tr>
<tr>
<td>Marital</td>
<td>.84</td>
<td>.08</td>
<td>-1.86</td>
<td>0.06</td>
<td>.69 - 1.01</td>
</tr>
<tr>
<td>Household</td>
<td>.87</td>
<td>.11</td>
<td>-1.12</td>
<td>0.26</td>
<td>.68 - 1.11</td>
</tr>
<tr>
<td>Household MM</td>
<td>.85</td>
<td>.19</td>
<td>-0.70</td>
<td>0.48</td>
<td>.55 - 1.33</td>
</tr>
<tr>
<td>Employment</td>
<td>1.07</td>
<td>.14</td>
<td>0.56</td>
<td>0.57</td>
<td>.83 - 1.38</td>
</tr>
<tr>
<td>Education</td>
<td>.89</td>
<td>.22</td>
<td>-0.44</td>
<td>0.65</td>
<td>.55 - 1.45</td>
</tr>
<tr>
<td>CD4</td>
<td>.51</td>
<td>.12</td>
<td>-2.92</td>
<td>0.004</td>
<td>.33 - .80</td>
</tr>
<tr>
<td>ECOG</td>
<td>1.23</td>
<td>.51</td>
<td>0.51</td>
<td>0.61</td>
<td>.55 - 2.78</td>
</tr>
<tr>
<td>_cons</td>
<td>1.21</td>
<td>1.83</td>
<td>0.13</td>
<td>0.90</td>
<td>.06 - 23.09</td>
</tr>
</tbody>
</table>
On the assessment of the prediction of interactions between variables, on the first model where pain is a dependent variable, there is a correlation between CD4 count of the participants and pain symptoms (p = 0.02). Taking the psychological symptoms as a dependent variable, the logistic regression indicated that there is significant evidence of a correlation between psychological symptoms and variable (education) with P-value = 0.02.

On the 3\textsuperscript{rd} model of other physical symptoms as a dependent variable, the logistic regressions predicted that there is enough evidence to support the correlation between physical symptoms and variables (Age (P=0.02), CD4(P = 0.004)
CHAPTER 5: DISCUSSION

5.1 Overview of the Discussion
This chapter contains a discussion of key findings of the results presented in the preceding chapters. The discussion includes the following: the socio-demographic characteristics, the prevalence of pain, symptoms (physical and emotional) of HIV patients and other relevant information of the study participants at Philip Moyo CHC.

5.2 Demographic Information
There were more than double female respondents (72.22 %) than male counterparts (27.78 %) in the sample. The relatively high number of females attending the clinic was not surprising and is consistent with Harding et al and Collins et al in different studies. This also reflects the demographic of HIV-infected persons, mainly females who access care in sub-Saharan Africa. Studies have found that females are more likely than males to check their HIV status and to actively seek health care. The findings relating to the high proportion of females at the Philip Moyo Clinic in this study also support other findings that HIV-infection is more common in women than in men, as confirmed by the findings of Shisana et al.

Regarding the age group of the respondents, more than 50 % were between the ages of 30 and 50 years old. The possible reasons could be that the prevalence of HIV is higher in this age group. Some patients in this age group may have been infected for a longer period and are now becoming sicker. It is notable that the mean age in this study was 38 years old which is similar to the findings in sub-Saharan Africa HIV palliative care population (36.7 years). Further logistic analysis showed age also as a contributory factor for the presence of physical symptoms. The physiological process of aging makes a person more vulnerable to a variety of sicknesses and health related problems.

Other demographic findings indicate that only 17 % of the respondents were in committed marital relationships; whereas the rest of the participants (83 %) were not. For the latter participants, these can be contributory factors for high risk behaviour, that is by exposing themselves to multiple and casual partners it opens the door to
acquiring HIV infection. These findings are supported by Shisana et al in a South African study that describes the prevalence of HIV as significantly higher in single persons compared with married couples.69

Over 75 % of the respondents were formally educated which gave them a better opportunity to better information and an understanding of the nature of the disease. However, the study showed there is a correlation between education and psychological distress. The more educated one is the more vulnerable to an emotional problem. It is noted from this study that: over 60 % of the participants were unemployed, the mean average of the total house numbers was four, and further exploration of the distribution showed that over 70 % of the house members were children and adult(s) without any income earnings. We clearly predicted that the levels of poverty, social issues and psychological problems were likely to be high.

5.3 Clinical Information

Almost 80 % of the respondents presented with a CD4 count of less than 500 which clearly indicated that the majority of them were significantly immune suppressed. Many studies indicated that most HIV patients presented with various physical and pain symptoms. However, despite the low average CD4 count, over 95 % of the participants were fully active and their functional status was very satisfactory.

The association between clinical factors as independent variables and pain, physical symptoms and psychological distress as dependent variables indicated an association between CD4 count and pain; and CD4 count and physical symptoms. This indicated that while the patients’ clinical conditions declined they eventually developed different types of clinical symptoms and pain distress. Our studies are supported by Merlin et al and Harding et al who showed in separate studies that the presence of physical symptoms are prominent in lower CD4 counts. 21,22

The APCA African POS results showed that the worst problems were pain, worry, life worthwhile and at peace which each scored “3” whereas physical symptoms, sharing of feelings and information to plan scored individually “2”. Although all the participants were on ARV medications, still feeling pain and psychological distress are the major challenges. Our findings are supported by similar studies, conducted in
sub-Saharan Africa by Harding *et al.* which reported on pain and physical symptoms of HIV patients.\(^{21}\)

During the interview, a detailed assessment of each symptom using ESAS (0=best and 10=worst) indicated that still the burden of pain (7), physical symptoms (6), emotional problems such as depression (6) and anxiety (5) were noted as the prominent problems in HIV patients despite the introduction of ARV medication. Seemingly, most clinicians have the expectation that ARVs and the counselling associated with ART will solve patients’ problems without considering other problems experienced by the patient and tend to focus only on the CD4 count.

With respect to symptom prevalence, it is interesting to note that both physical and psychological problems were among the five most prevalent symptoms. The prevalence of pain symptoms was the highest (90.7 %) followed by depression (87.04 %) and anxiety (80.86 %) - these findings are supported by similar studies in the sub-Saharan region conducted by Farrant *et al.* and Collins *et al.*\(^{37,55}\). However, in this study only 30 % of respondents received pain medications which were far below the expected. Among those who were given a chance to receive pain medication, simple analgesia accounted for more than 80 % thereof.

It is noted that although pain is very common in HIV patients, its management seems neglected. The overall assessment of pain management at this clinic was very poor. It was found that by using the PMI assessment 80 % of the participants had their pain symptoms treated inappropriately which means not to the recommended level of WHO pain management. Our findings are supported by studies in sub-Saharan Africa conducted by Harding *et al.* and Farrant *et al.* which describe pain as the prominent problem of HIV disease, and under treated.\(^{21,37}\)

Other studies have contrary findings indicating that better attention to pain management in HIV care is provided in the current era of HAART, as described by Fox *et al.*\(^{70}\)

The high prevalence of physical and psychological symptoms is a key finding of this study and is supported by other studies among HIV patients with symptoms distributing across psychological and physical domains, despite being put on ART.\(^{71}\)
These findings highlight the importance of integration of the comprehensive response of palliative care into HIV care; palliative care being described by WHO as, ‘impeccable assessment and treatment of pain and other distressing problems, physical, psychosocial and spiritual’.\textsuperscript{72, 73} Pain was a common symptom in our study. These and other symptoms require adequate acknowledgement and assessment, and appropriate, acceptable and effective treatment to prevent on-going problems.

The high prevalence and burden of symptoms experienced by our participants suggest inadequate symptom control. It highlights the palliative care needs of patients treated in community health clinics, of all who are receiving ART. Our findings strongly argue for palliative interventions for HIV patients ‘in conjunction with other therapies that are intended to prolong life’.\textsuperscript{72, 73} Extension of life without addressing quality of life is ethically unjustifiable. The focus should be not only to treat the disease alone with drug therapy but rather to treat the patient holistically. Palliative care aims to ‘enhance quality of life, and may also positively influence the course of illness’ by using ‘a team approach to address the needs of patients and their families’ and to treat for the ‘relief from pain and other distressing symptoms’\textsuperscript{74}.

### 5.4 Limitation of Study

There are a few limitations to our study and data. The study was only conducted at one clinic and the results may not be generalized to other health settings in South Africa. The study used a cross-sectional design. With this design, no conclusion about causal links can be drawn. For this reason, prevalence is a mixture of incidence and duration of the disease; cross-sectional studies have challenges in distinguishing between factors that cause the disease and those that prolong the disease\textsuperscript{67}. Another limitation is that in this study we used APCA POS as a single measurement rather than following-up patients to assess outcomes of treatment so there was no assessment of improvement or decline over a period of treatment.
CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

The study showed a high prevalence of pain symptoms and high symptoms burden experienced by the participants which is a clear demonstration that the symptoms are inadequately controlled, and highlighted the needs of palliative care for an ambulant patient population already receiving HAART. Of significance and concern is the fact that few patients experienced adequate pain management as defined by the Pain Management Index (PMI).

Since the introduction of antiretroviral, HIV is considered as a chronic disease for those on treatment. The concept of ‘living well’ with HIV becomes clinically important as treatment access expands and patients and clinicians have greater expectations of reducing morbidity and mortality. However, HIV patients may have a different level of distressing but manageable problems, including pain, worry and depression, social problems, spiritual distress, lack of information, and impaired well-being. There is evidence that HIV palliative care can be effective in the spectrum of pain, symptoms, anxiety, insight, and spiritual well-being. Better outcomes can be achieved and patient’s retention in care may be improved. It is clear from the literature that many HIV symptoms and problems are unidentified by clinicians, and from our review that multidimensional problems are present from the point of diagnosis. Therefore, from diagnosis onward, quality HIV care must include assessment of multidimensional problems and the integrated palliative care approach for effective management of HIV patients.

To enable patients to live a good quality of life, the burden of the infection and its treatment must be minimized. The current focus of HIV clinical care is on viral suppression with little attention being paid to the patient’s experience of the disease, despite a high symptom burden in HIV illness that persists even in the presence of treatment. In general, health workers tend to overlook the assessment of pain and other treatable symptoms and those due to drug side effects; they focus on symptoms that are physically measurable, such as fever and weight loss, and on patients perceived to be severely ill, and they are more vigilant in asking about symptoms in these situations. This study shows that healthcare workers should not
assume absence of symptoms unless a detailed history has been taken. Although the prevalence of symptoms may be high and persist alongside treatment, pain and other symptoms can be controlled effectively by HIV palliative care.

To generate locally relevant data, we measured the prevalence and burden of pain and other physical and psychological symptoms among HIV patients accessing HAART in CHC sector's HIV clinics.

In conclusion, collaborative efforts in keeping with the palliative approach are required to address physical and psychological symptoms experienced by HIV patients in South Africa (SA).

6.2 Recommendations

Based on the findings of the study, the researcher makes the following recommendations:

- Train and equip health workers or service providers in palliative care as appropriate to the primary care level; as recommended by the World Health Assembly resolution (WHA67.19)\(^4\)
- Establish multidisciplinary teams at primary health care level which involve palliative care service. Assess and fill gaps in current teams related to palliative care.
- Establish standardized pain and other symptoms assessment tools as part of routine patient intake and follow-up forms for HIV patients
- Ensure identified symptoms are managed for optimal reduction of patient suffering
- Implement pain management protocols
- Ensure availability of relevant primary care palliative care medicines on the service essential drug list.
- Develop a brief psychosocial assessment as part of patient intake and follow-up forms.
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APPENDICES

APPENDIX 1: MRC UCT ETHICAL CLEARANCE

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7928
Telephone (021) 406 6339 Fax (021) 406 6414
Email: hrec@fsa.uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

25 September 2015

HREC REF: 569/2015

Dr L Gwyther
Public Health & Family Medicine
Level 2
Falmouth Building

Dear Dr Gwyther

PROJECT TITLE: AN EVALUATION OF PALLIATIVE CARE NEEDS FOR HIV PATIENTS IN THE CONTEXT OF HAART OF PHILP MOYO CLINIC, GAUTENG PROVINCE (MPhil-candidate M Eyassu)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has formally approved the above-mentioned study.

Approval is granted for one year until the 30th September 2016.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

We acknowledge that the student Dr M Eyassu will also be involved in this study.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

Signed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH

HREC 569/2015

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APPENDIX 2 EKURHULENI ETHICAL CLEARANCE CERTIFICATE

EKURHULENI RESEARCH CLEARANCE CERTIFICATE

Research Project Title: Palliative care needs for HIV patients in the context of HAART at Philip Moyo Clinic, Gauteng province.

Research Project Number: 1007/2015-1

Name of Researcher(s): Dr. Melaku Eyassu

Division/Institution/Company: School of Health Sciences, University of Capetown

DECISION TAKEN BY THE EKURHULENI HEALTH DISTRICT RESEARCH COMMITTEE (EHRDC)

- THIS DOCUMENT CERTIFIES THAT THE ABOVE RESEARCH PROJECT HAS BEEN FULLY APPROVED BY THE EHRDC. THE RESEARCHER(S) MAY THEREFORE COMMENCE WITH THE INTENDED RESEARCH PROJECT.
- NOTE THAT THE RESEARCHER WILL BE EXPECTED TO PRESENT THE RESEARCH FINDINGS OF THE PROPOSED RESEARCH PROJECT AT THE ANNUAL EKURHULENI RESEARCH CONFERENCE.
- THE RESEARCH COMMITTEE WISHES THE RESEARCHER(S) THE BEST OF SUCCESS.

Signed

DEPUTY CHAIRPERSON: EKURHULENI METROPOLITAN MUNICIPALITY
Dated: 15/07/2015

Signed

CHAIRPERSON: GAUTENG DEPARTMENT OF HEALTH (EKURHULENI REGION)
Dated: 15/07/2015
Thank you for giving your time to hear about our study.

This information sheet tells you about a study that you may wish to take part in. You may have some further questions to help you decide whether you want to take part. You can ask any further questions from your clinical team, from the researcher, or using the telephone numbers at the end.

Thank you for thinking about whether you want to take part. Please take your time to make a decision.

**What is the purpose of the study?**

We are looking at how people's care needs and how these needs are helped by the different services people may access.

**Do I have to take part?**

No, you don’t have to take part. If you do agree to take part, you are free to withdraw from the interview at any time without giving us any reason. Whether or not you take part, your care will NOT be affected in ANY WAY. If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part, and you may want to talk it over with your family, friends or someone in your care team.

**What will happen if I take part?**

An experienced researcher will speak to you and ask you questions about you and your health, and this may include any pain or other problems you have. It will take around 10-15 minutes. This information sheet is for you to keep.

**Benefits of the study**

There are no direct benefits to the study for participants although people who have been interviewed using these questionnaires find that they are good points for discussion.
with care providers. The anticipated benefits are in identifying people’s care needs and in trying to meet those needs.

**What are the risks of the study?**
There are few study risks. Answering some questions might cause and emotional response. The researchers and counselors are trained to assist if the questions cause an emotional response. The researcher will stop the study and ask you if you would like assistance.

**Will my taking part in this study be kept confidential?**
All the information which we collect during the interview will be kept strictly confidential. You will not be identified in any way, and your personal details (for example name and address) will be kept separately from the information you give. We will use a number and not your name on any information you give us. No-one outside the study will have access to the information you give us.

For patients in this study we will record their illness. That information will be treated as confidentially as all the other information you give us, and no-one outside this study will be able to find out your name or any other information that would identify you.

**How will I know about the results of the study?**
At the end of the study a report will be sent to the clinic/outpatient department and to the people who took part in the study.

**Who is organising the research?**
If you need to talk to anyone about this research, you can contact the following people.

If you have any questions about the study:  
**DR MA EYASSU CEL  0824202039; EMAIL  
meyassu@hotmail.com**

If you have any questions about your human rights or any ethical issues about the study:  
**UCT Research Ethics Committee:**  
Mrs Lamees Emjedi

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone:  ”021 406 6338"
APPENDIX 4: CONSENT FORM

Consent form for: The Right to Health in South Africa: access to care

1. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without being affected.

3. I agree to take part in the above study.

Name ______________________________________

Signature ________________________________ Date __________________

Witness: Name
(from clinical team or family member)

Signature ______________________________ Date:

___________________
APPENDIX 5: DATA COLLECTION TOOL

QUANTITATIVE DATA COLLECTION TOOL (STRUCTURED QUESTIONNAIRE)

(A) Basic Information
1. Date of interview.____________________
2. Study site._________________________
3. Participants No ................................

(B) Socio-Demographic Information

4. Sex/ Gender of participant (1) Male [ ] (2) Female [ ]

5. Age in years: ........

6. What is your current marital status?

1). Single (not married and not living with a partner) [ ]
2) Married (monogamous/polygamous) [ ]
3). Separated (currently not living together but not divorced) [ ]
4) Divorced [ ]
5) Widowed/ widower [ ]
6) Co-habiting (not married but lives with a partner) [ ]

7). Number of house hold..............................

8) People in the house hold
1) children 2) adult(s) without earning 3) adult(s) who earning

9). what is your employment status?
1) Employed with job [ ]
2) Business/self-employed. [ ]
3) Pensioner [ ]
4) Unemployed [ ]

10). What is your level of education?
1) No formal education [ ]
2) Primary education [ ]
3) Secondary education [ ]
4) Tertiary [ ]

C. Clinical information
11. HIV Stage 1, one 2. Two 3. three 4. Four

12. Current CD4 count 1. <100 2. 100-200 3. 200-500 4. >500

13. Prescribing of analgesia 1. YES 2. NO
Specify …..


1. step 1..... 2. Step 2 3. Step 3…
## D. PAIN AND SYMPTOMS ASSESSMENT

### 15. APCA AFRICAN POS

<table>
<thead>
<tr>
<th>ASK THE PATIENT</th>
<th>POSSIBLE RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days</td>
<td>0 (no pain)- 5 (worst/overwhelming pain)</td>
</tr>
<tr>
<td></td>
<td>0 □ 1 □ 2 □ 3 □ 4 □ 5 □</td>
</tr>
<tr>
<td>Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?</td>
<td>0 (not at all)- 5 (overwhelmingly)</td>
</tr>
<tr>
<td></td>
<td>0 □ 1 □ 2 □ 3 □ 4 □ 5 □</td>
</tr>
<tr>
<td>Q3. Have you been feeling worried about your illness in the past 3 days?</td>
<td>0 (not at all)- 5 (overwhelming worry)</td>
</tr>
<tr>
<td></td>
<td>0 □ 1 □ 2 □ 3 □ 4 □ 5 □</td>
</tr>
<tr>
<td>Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?</td>
<td>0 (not at all)- 5 (yes, I’ve talked freely)</td>
</tr>
<tr>
<td></td>
<td>0 □ 1 □ 2 □ 3 □ 4 □ 5 □</td>
</tr>
<tr>
<td>Q5. Over the past 3 days have you felt that life was worthwhile?</td>
<td>0 (no, not at all)- 5 (yes, all the time)</td>
</tr>
<tr>
<td></td>
<td>0 □ 1 □ 2 □ 3 □ 4 □ 5 □</td>
</tr>
</tbody>
</table>
**Q6.** Over the past 3 days, have you felt at peace?

0 (no, not at all) - 5 (Yes, all the time)

[ ] 0  [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5

**Q7.** Have you had enough help and advice for your family to plan for the future?

0 (not at all) - 5 (as much as wanted)

[ ] 0  [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5

---

**16. Edmonton Symptom Assessment System:** (revised version) (ESAS-R)

**Please circle the number that best describes how you feel NOW**

<table>
<thead>
<tr>
<th>Level of symptoms</th>
<th>symptoms</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst possible symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No pain</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Worst possible pain</td>
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<tr>
<td></td>
<td>No tiredness</td>
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<td></td>
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<td></td>
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<td></td>
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<td></td>
<td>Worst possible tiredness</td>
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<td></td>
<td>Tiredness=lack</td>
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<td>Worst possible drowsiness</td>
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<td></td>
<td>of energy</td>
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<tr>
<td></td>
<td>No Drowsiness</td>
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<td>(feeling sleepy)</td>
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<td></td>
<td>No nausea</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Worst possible nausea</td>
</tr>
<tr>
<td></td>
<td>No lack of appetite</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Worst possible lack of appetite</td>
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<tr>
<td>6</td>
<td>No shortness of breath</td>
<td></td>
<td></td>
<td>Worst possible shortness of breath</td>
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</tbody>
</table>
| 7 | No depression
Depression = feeling sad |   |   | Worst possible depression |
| 8 | No Anxiety
Anxiety = feeling nervous |   |   | Worst possible anxiety |
| 9 | No wellbeing
(Wellbeing = how you feel overall) |   |   | Worst possible wellbeing |
| 10 | Other problems eg. constipation |   |   | Worst possible problem |

E. functional status

17. ECOG

1. Fully active
2. Restricted
3. Ambulatory
4. Limited self-care
5. Fully disabled