IDENTIFICATION OF THE MOST PREVALENT SYMPTOMS AND SITES OF PAIN EXPERIENCED BY AIDS PATIENTS AT SOWETO HOSPICE, JOHANNESBURG, SOUTH AFRICA

BY

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ABSTRACT

The aim of this study was to identify the ten most prevalent symptoms and five of the most common sites of pain in a patient with advanced AIDS. The setting was a Hospice In-Patient and Home Care program in Soweto, Johannesburg, South Africa. Soweto has a population of approximately 3.5 million.

The design was a descriptive quantitative analysis using a nurse-led questionnaire to collect data and was completed in 3 different languages. The patients included 103 adult patients with WHO Stage 4 AIDS who were alert enough and willing to participate. Patients with impaired cognitive function were excluded from the study.

The main outcome measures included a list of 30 symptoms, 13 site-specific pains, age, gender, worst overall pain and/or symptom and access to antiretroviral therapy. The results were based on the review of data collected from 103 patients between May 2002 and February, 2003.

The results showed the mean age of patients to be 35.4 years, females being an average of 4.4 years younger than males. There was a higher number of female respondents (62.63%) compared to males (37.37%). The ten most common symptoms in order of prevalence were pain (98%), loss of weight (81%), loss of appetite (70.87%), low mood (69.9%) weakness (66%), dry skin (56.3%), diarrhoea (53.4%), nausea and vomiting (44.7%), cough (44.7%) and fatigue (42.7%).

34.38% of respondents mentioned pain as being their worst overall symptom. The average number of pains experienced was 2.91. Female respondents reported significantly more anxiety and genital sores and pain. 3.88% of patients had had access to ART. Lower limb pain was the most prevalent pain (66%) followed by mouth pain (50.5%), headache (42.3%), throat pain (39.8%) and chest pain (17.5%).

Conclusions drawn were that patients with advanced AIDS suffer significantly from pain and a number of distressing symptoms. In the light of the HIV/AIDS pandemic in SA, and the lack of access to ART, reforms are needed to increase knowledge and education in Palliative Care. There is a

need for the development of standard protocols for the palliative management of AIDS-related pain and symptoms and more research into end-of-life care for these patients.

CONTENTS

CHAPTER 1 : BACKGROUND TO THE STUDY

1.1 INTRODUCTION

AIDS patients present with some symptoms common to all patients with advanced disease, such as pain, nausea and fatigue.

However, patients with advanced AIDS also present with unique and challenging symptoms and pain syndromes. This is especially so in the South African context where the large majority of patients do not have access to anti-retroviral therapy (ART). For many reasons, AIDS has not yet become a chronic manageable disease in South Africa and patients are dying from the illness at an alarming rate.

This study aims to identify the ten most prevalent symptoms and five most prevalent sites of pain suffered by patients with AIDS. This will lead to the development of protocols for the effective palliative management of each of these pain and symptoms regardless of aetiology.

Modern medical AIDS management rightly focuses on the use of ART as well as identifying and treating opportunistic infections and cancers, but there is very little focus on the patient as a whole, or on managing distressing symptoms. These issues are particularly relevant at Soweto Hospice where the vast majority of patients with AIDS have no access to ART. Soweto Hospice is set in an urban environment and is a branch of Hospice Witwatersrand in Johannesburg. Soweto Hospice has a Home Care programme, Day Care Centre and a 10-bed In-Patient Unit. The vast majority (80%) of patients seen at Soweto Hospice have AIDS.

1.2 RESEARCH QUESTION

What are the ten most prevalent symptoms and five most prevalent sites of pain experienced by a patient with advanced WHO Stage 4 AIDS in an urban setting?

1.3 GOALS OF THE STUDY

1. Identify the ten most prevalent symptoms and five most prevalent sites of pain of AIDS patients registered with Hospice Soweto.
2. Differentiate between pain and symptoms in males and females.
3. Identify which pain causes the most distress overall.
4. Identify which symptom causes the most distress overall.
5. Determine the number of patients who have had access to ART.
6. Determine the average number of symptoms and sites of pain experienced by a patient with advanced disease.

1.4 OBJECTIVES

Primary Outcomes

Increase awareness of the ten most prevalent presenting symptoms and the five most prevalent sites of pain of AIDS patients at Soweto Hospice.

Secondary Outcomes

- To stimulate further investigation into the likely aetiology of each pain and symptom
- Design on-the-job aids detailing Palliative Management Protocols for each of these pains and symptoms for use by doctors and nurses working in resource-poor settings; Examples : laminated pocket book, posters, pamphlets
- To improve the focus of Palliative Care education and training in SA by identifying common patterns of pain and symptomatology in AIDS.

CHAPTER 2 : LITERATURE REVIEW

HIV/AIDS-related literature in South Africa at present focuses much on the potential use of anti-retroviral drugs (1, 2), prevention of mother-to-child transmission (3, 23), governmental policies and attitudes (4, 5), epidemiology (6), vaccine trials (7, 8) and factors in this region causing such rapid spread of the virus (9, 10).

Most HIV/AIDS textbooks and guidelines discuss at length the different opportunistic infections and their management, such as the management of Tuberculosis, Pneumocystis Carinii Pneumonia, Cryptococcal infections, Candidiasis and Cytomegalovirus Infection. Textbooks and literature also focus on AIDS related syndromes and tumours such as Progressive Multifocal Leucoencephalopathy, Lymphomas and Sarcomas (11, 12, 13 and 21).

Very little emphasis is placed on the palliation of AIDS related symptoms such as pain, cough, dyspnoea, diarrhoea, anorexia, nausea, pruritis or malaise. Further, health care professionals are frequently guilty of shedding responsibility of the care of the patient with an attitude of "there is nothing more that can be done." (14).

Palliative Care is seen as important at all stages of HIV disease (16) but some see Palliative Care as a form of treatment only to be instigated when a patient has a very poor prognosis or a World Health Organisation Staging System performance scale of 4 (bed-bound for more than half the day for a month) (15). However, Palliative Care includes the active treatment of reversible conditions and opportunistic infections as well as the effective management of symptoms with or without the benefit of ART.

A review of earlier literature on HIV/AIDS reveals a greater emphasis on symptom control. This was in the early days of the epidemic when ART was not readily available. Kemp & Stepp (1995) list various symptoms commonly experienced by patients with AIDS and advise on Palliative management. (17)

More recent literature focuses largely on the effects of ART and less on symptom control. Frich et al (2000) reports that there are no reports in the literature concerning the incidence of pain, and despite the high incidence of pain, the published literature is scarce (18)

There is a similar lack of literature on the incidence of AIDS related symptoms. Fontaine et al (1999) states that "Symptom control should be part of the management of all patients and should be an essential component of patient care at all stages" (19).

In South Africa, management of AIDS related symptoms should be an integral part of the care of our patients, the majority of whom, have no access to ART.

A study done in France in 1992 assessed how well physicians recognised common symptoms in HIV patients at all stages of the disease. They found that physicians pay more attention to objective clinical findings than to subjective reports of symptoms (19).

The existing literature available on pain management in AIDS is often limited to studies conducted with health care providers who treat cancer pain (20, 16). Little mention is made of specific AIDS related pain syndromes or their management.

If in future, patients with HIV/AIDS in South Africa have widespread access to ART, and AIDS becomes a more chronic manageable disease, Palliative Care will still be needed as new challenges arise such as treatment failure, resistance due to non-adherence or drug toxicity. A study on advanced Stage HIV patients by Brechtl et al (2001) showed that even with the use of ART, ratings of pain intensity, physical and psychological symptom distress did not change. (48)

Even though current antiretroviral therapy is much more successful at prolonging reasonably good health, severe illnesses are likely to emerge eventually in this population. Symptom control will still be a vital part of management. Palliation and attempts at cure cannot be separated. (22).

This research aims to focus on symptoms experienced specifically by South African patients with advanced AIDS and to elicit the most prevalent and distressing of these pains and symptoms. It is hoped that documentation of the incidence of pain and symptoms will highlight the need for effective palliation and help health care professionals focus on the patient and not just on the disease.

CHAPTER 3 : RESEARCH METHODOLOGY AND DESIGN

3.1 RESEARCH DESIGN

For the purpose of this research, a descriptive study using quantitative analysis was used. The quantitative approach produced numerical and factual data that provided a statistical and numerical analysis of the phenomenon of advanced AIDS.

3.2 STUDY POPULATION AND SAMPLING

The study sample of 103 hospice in-patients and out-patients was drawn from adult patients registered with the Soweto Hospice Program between May 2002 and February, 2003.

Selection of Subjects

- AIDS patients registered with Hospice Association of the Witwatersrand (WHO Clinical Stage 4)
- Admission to in-patient unit - Soweto or registered on Home Care Program
- Confirmed positive HIV test
- Any age over 18
- Willingness to sign consent for interview.

Exclusions

1. Reduced level of consciousness or HIV-related dementia resulting in Glasgow Coma scale < 12
2. HIV status undisclosed / unconfirmed
3. Unwillingness to take part in the study

The study population was highly selected in that participation in the study was voluntary and included patients with a diagnosis of AIDS who were willing and alert enough to answer questions.

All patients included in the study were classified as Stage 4 in the WHO staging system for HIV infection and disease. (Annexure D)

A large percentage of patients were excluded from the study due to cognitive impairment relating to AIDS dementia, delirium and drowsiness. Others were too ill with a reduced level of consciousness. Another indication for exclusion was unconfirmed HIV status. Those unwilling to participate where also excluded.

Of the 440 AIDS patients registered with Soweto Hospice during this 9 month period, 103 participated in the study.

3.3 SETTING

Soweto Hospice is primarily an AIDS Hospice situated in the urban area of Mofolo, Soweto, a large suburb of Johannesburg, South Africa. Patients are admitted to the 10-bed in-patient unit for pain and symptom control, respite care and terminal care. A large Home Care program is managed by doctors, professional nurses and social workers with the help of community care workers. Home-based Care is the cornerstone of the Soweto Hospice Program.

The site was chosen for this study because of the relatively high prevalence of HIV/AIDS in this area. In Johannesburg in general, the incidence of HIV/AIDS amongst adults aged 15-49 years is 29%. This figure is taken from the antenatal clinic survey. In Soweto the incidence is 32%. (25)

3.4 DATA COLLECTION METHOD

Prospective analysis was made upon initial referral to the in-patient unit or home care program.

A two-page structured questionnaire was used to collect data during nurse-led interviews with patients. The interviewers were 5 professional Palliative Care nurses working in the Soweto in-patient unit and Home Care program. They received training on the use of the questionnaire and interview techniques, confidentiality and ethical issues, obtaining patient consent,

determining which patients could be included or excluded from the study and revision of the Glasgow Coma Scale.

All questionnaires were read to patients to minimise patient burden and fatigue.The questionnaires were translated from English into Zulu and South Sotho, the three most frequently used and understood languages in Soweto. Questionnaires were read to patients in the language they were best able to understand

The questionnaires were used to collect data on patient age, gender, 26 symptoms specific to the central nervous system, gastrointestinal system, dermatological and respiratory systems. Four general symptoms such as fatigue and fever were also recorded. 13 site-specific pains were recorded. Each pain/symptom was recorded as present or absent. Respondents were requested to state the worst pain and the most severe overall symptom (including pain). Words describing pain were documented e.g. 'burning' 'stinging'.

Lastly, respondents were asked whether or not they had ever had access to anti-retroviral therapy. (Annexure A)

3.5 CONSENT

Voluntary participation with informed consent was obtained before questioning. Consent forms were available in English, Zulu or South Sotho. Participants were all able to sign the consent form and there were no problems obtaining consent. (Annexure B) The consent procedure included explanation of the aims of the study and the patient information leaflet using the language best understood by the patient. The patient information leaflet was kept by the patient. The patient was read the consent form, and those who wanted to could read it as well. The patient signed the consent form which was kept in CPL records separate to the questionnaires which were anonymous. This was done in order to ensure confidentiality.

A patient information leaflet explaining the project was available in English, Zulu and South Sotho. (Annexure C)

3.6 ETHICAL CONSIDERATIONS

Permission to undertake the study was obtained from the Executive Director of Hospice Association of the Witwatersrand and the Research Ethics Committee of the Health Sciences Faculty at the University of Cape Town. The ethical code of practice and the principles laid out in the Declaration of Helsinki are adhered to in this research project. (51) The consent forms were kept separate to the questionnaires which were anonymous. Every effort to maintain confidentiality and privacy was made.

3.7 PILOT STUDY

A pilot study was carried out in April 2002 on six patients before commencing the formal research. It was a valuable exercise as it revealed that 'backache' as a site of pain had been omitted. This was subsequently added to the questionnaire.

There were no other criticisms or comments by the interviewers or patients and the questionnaire was believed to be suitable, simple to use and took a small (about 10 minutes) amount of time to complete.

3.8 DATA ANALYSIS

Statistical analysis was performed using Excel software.

The data gathered was captured in a spreadsheet, where each row represented each participant's answers to the questions.

The age field was numeric, and therefore some statistical analysis could be applied to the data. The gender field was text, and all other fields included an indicator variable, depending on whether the respondent answered positively (1) or negatively (0) to each question. With fields that were not strictly numeric, it was not possible to apply advanced statistical methods, but it was rather more relevant to analyse the data through descriptive methods.

Because of the small sample size, it was unlikely that any conclusions could be drawn from a correlation analysis. Any conclusions drawn would be spurious. The data is also not in the correct format to undertake in-depth correlational analysis. There was more value in analysing the data in tabular form.

Given the format of the information that was being analysed, it was not relevant to use the chi-square test as the research is not fitting a statistical distribution to the observed data.

A simple spreadsheet calculation was used to count the number of patients by both age group and gender. The averages calculated were the simple arithmetic averages of the observed values - for the entire sample, and for each of the gender sub-samples.

In determining the percentage of patients who could afford anti-retroviral drugs, a simple summation of the results provided the results.

In analysing different symptoms and pain, a simple Excel summation by symptom/pain and gender produced the tables.

CHAPTER 4 : RESULTS

The purpose of this research project is to provide information regarding the age, gender, symptoms and pains experienced by 103 observed AIDS patients. In the sections below, specific results of the data analysis are considered.

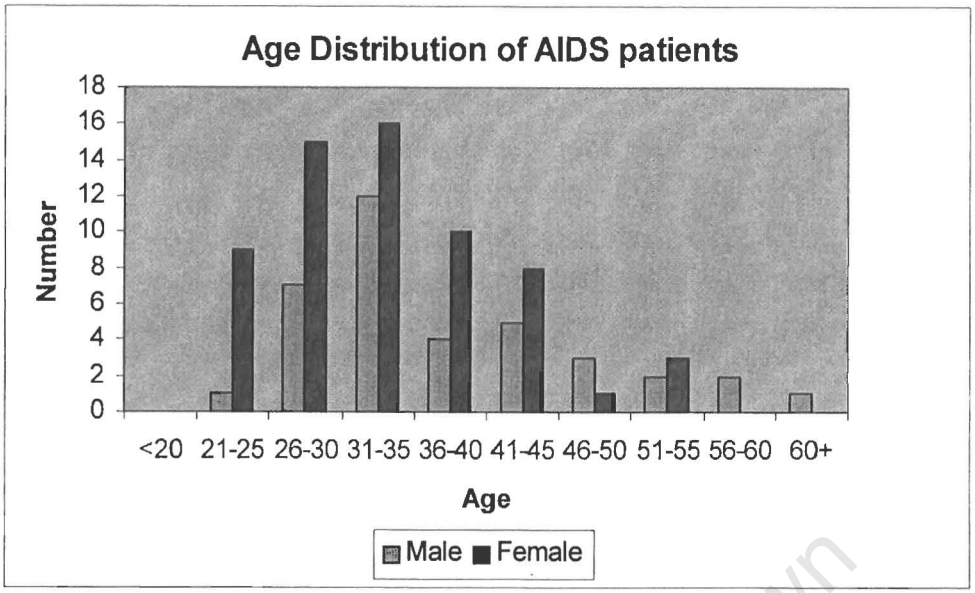
4.1 DEMOGRAPHIC PROFILE

Table 1 represents the demographic profile of the 103 observed patients (4 patients did not declare gender):

TABLE 1: Age	Male respondents	Female respondents	Study population
21-25	1	9	10
26-30	7	15	22
31-35	12	16	28
36-40	4	10	14
41-45	5	8	13
46-50	3	1	4
51-55	2	3	5
56-60	2	0	2
60+	1	0	1
Total no.	37	62	99
Percentage of study population	37.4%	62.6%	

Figure 1 represents the demographic profile in the form of a histogram:

Figure 1:



Age data was provided for each of the 103 patients, but 4 patients did not declare their gender. This explains the total of 99 above, which is 4 short of the observed number of patients.

Male patients comprised approximately 37.37% of the sample, and female patients the remaining 62.63%

The above table (and supporting data) implies the following:

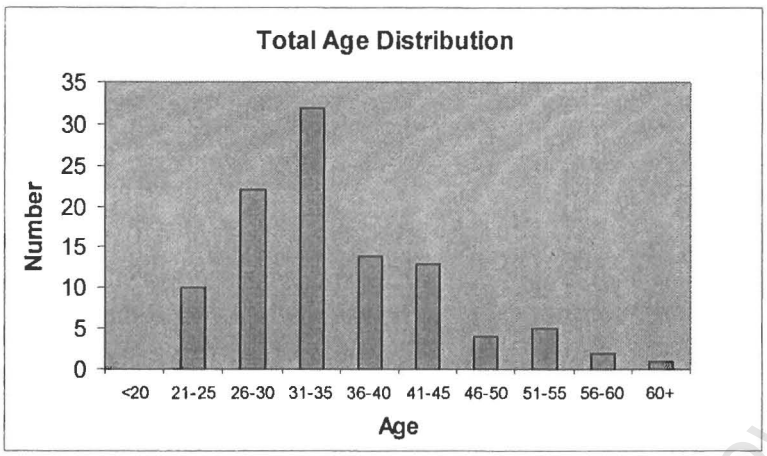
- Average age of male patients is 38.3 years
- Average age of female patients is 33.9 years

It is noticeable that female patients are on average 4.4 years younger than their male counterparts. It is widely accepted that for various reasons females have higher infection rates than men (which may explain the higher proportion of female patients even in this small sample), and that females are infected younger than men, which certainly supports the observed data above. (25)

So, whilst there is a significant difference between observed average ages, it is not a cause for concern, and therefore does not bias the analysis in any way.

Figure 2 presents data looking at age only

Figure 2:



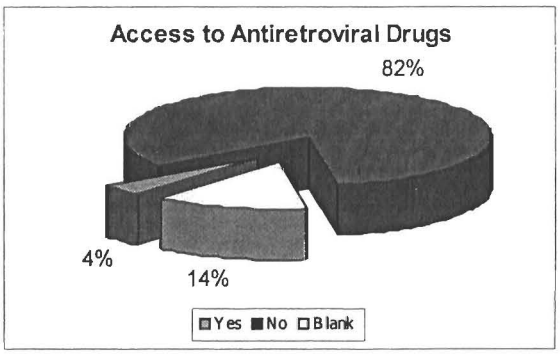
This table (and the supporting data) implies the following:

- An average age of observed AIDS patients of 35.4 years
- A standard deviation in the observed AIDS patients' ages of 8.8 years. This describes the spread of the observed ages around the mean value of 35.4 years. The conclusion must be that the observed ages are well concentrated around the mean.

4.2 ACCESS TO ANTIRETROVIRAL THERAPY

Figure 3 summarises the results of the percentages of patients who had had access to ART.

Figure 3:



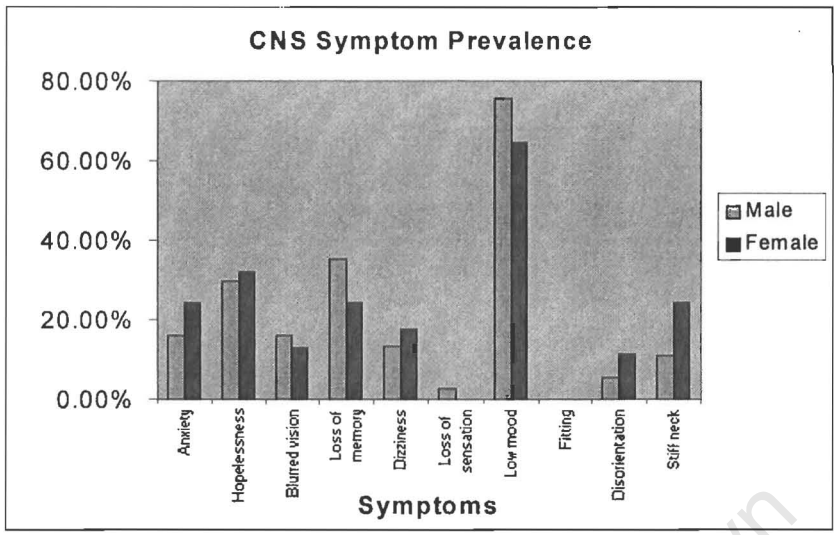
There were 14 (13.6%) non-respondents to the question of whether or not each patient had access to antiretroviral medication. 4 (3.88%) patients had access to ART. 85 (82.5%) patients had not had access to ART.

Only 3.88% of all patients and 4.5% of respondents (4 of the 89 that replied) have had access to ART.

4.3 ANALYSIS OF CNS SYMPTOMS

Figure 4 splits, by gender, the total number of patients experiencing a particular symptom.

Figure 4:



- Interestingly, males and females both identified "low mood" as the major CNS symptom.
- The top 3 CNS symptoms for males were "low mood" (75.68%), "loss of memory" (35.14%), and "hopelessness" (29.73%).
- The top 3 symptoms for females were "low mood" (64.52%), "hopelessness" (32.26%) and the same proportion of observations (24.19%) for "anxiety", "loss of memory" and "stiff neck".
- The sum of the male and female responses do not in all cases add up to the total, due to the 'blank' results for gender described in the 'demographic profile' section. (4 patients did not declare gender)
- The weighting of results by gender was also considered, by applying the proportion of males and females to the total observed number of responses for each symptom, and compared those to the actual observed responses by gender. It would be imprudent to place a large amount of credibility on this result, primarily due to the overall sample size, as this may generate spurious conclusions.

Table 2 summarises the results of the analysis of the CNS symptoms experienced by both males and females.

TABLE 2:

	Total	Percentage	Male	Female	Sum
Anxiety	21	20.39%	6	15	21
Hopelessness	32	31.07%	11	20	31
Blurred vision	14	13.59%	6	8	14
Loss of memory	31	30.10%	13	15	28
Dizziness	16	15.53%	5	11	16
Loss of sensation	1	0.97%	1	0	1
Low mood	72	69.90%	28	40	68
Fitting	0	0.00%	0	0	0
Disorientation	9	8.74%	2	7	9
Stiff neck	20	19.42%	4	15	19

- The first two columns of the table represent the results of all respondents. For example, 16 of the respondents said that they experience "dizziness" as a symptom. This represents 16 of 103 patients, which is equivalent to 15.53%.
- From this it can be deduced that "low mood" (69.9%) is the most prevalent CNS symptom experienced, followed by "hopelessness" (31.07%), "loss of memory" (30.10%), "anxiety (20.39%), "stiff neck" (19.42%), "dizziness" (15.53%), "blurred vision" (13.59%), "disorientation" (8.74%) and "loss of sensation" (0.97%). No patients experienced "fitting" as a symptom.

4.4 ANALYSIS OF GASTROINTESTINAL SYMPTOMS

Table 3 summarises the results of the analysis of the GIT symptoms experienced by both males and females.

Table 3:

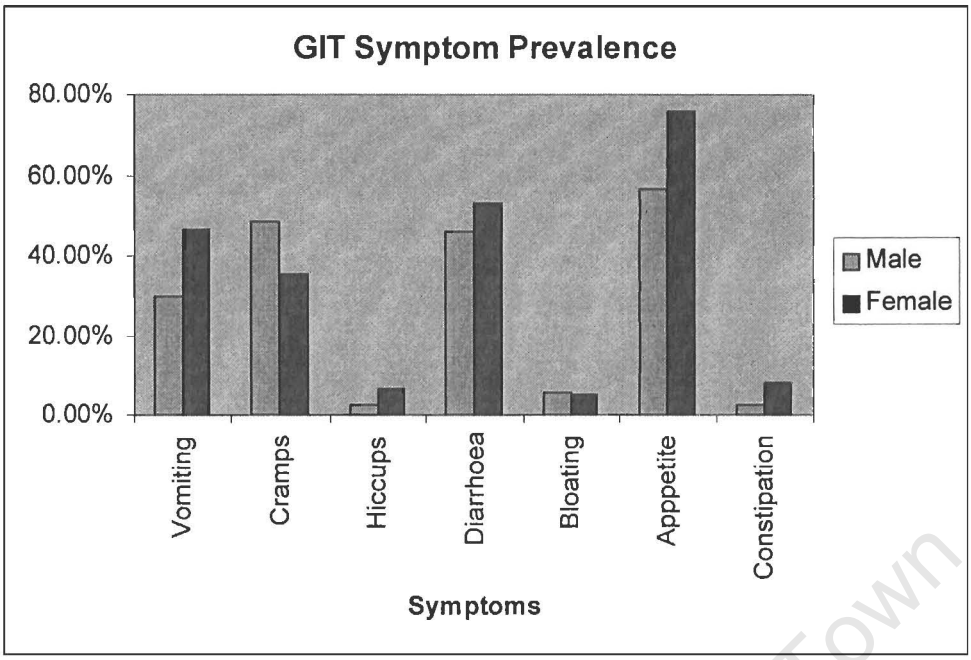
	Total	Percentage	Male	Female	Sum
Nausea & Vomiting	46	44.66%	11	29	40
Cramps	43	41.75%	18	22	40
Hiccups	5	4.85%	1	4	5
Diarrhoea	56	53.40%	17	33	50
Abdominal Bloating	4	3.88%	2	3	5
Loss of Appetite	73	69.90%	21	47	68
Constipation	6	5.83%	1	5	6

From this it can be deduced that "loss of appetite" (69.9%) is the most prevalent gastrointestinal tract-related symptom followed by "diarrhoea" (53.4%), "nausea and vomiting" (44.66%) and "abdominal cramps" (41.75%).

"Hiccups" (4.85%), "abdominal bloating" (3.88%) and "constipation" (5.83%) were not often reported.

Figure 5 further splits, by gender, the total number of patients experiencing a particular GIT symptom:

FIGURE 5:



- Interestingly, males and females both identified "loss of appetite" as the major symptom, however, more females (75,81%) compared to males (56.76%) complained of this symptom.
- The top 4 GIT symptoms for males: "loss of appetite", "diarrhoea", "nausea" and "vomiting" and "abdominal cramps", corresponded to the top 4 GIT symptoms in females.

4.5 ANALYSIS OF RESPIRATORY SYMPTOMS

Table 4 summarises the results of the analysis of the respiratory symptoms experienced by both males and females.

TABLE 4:

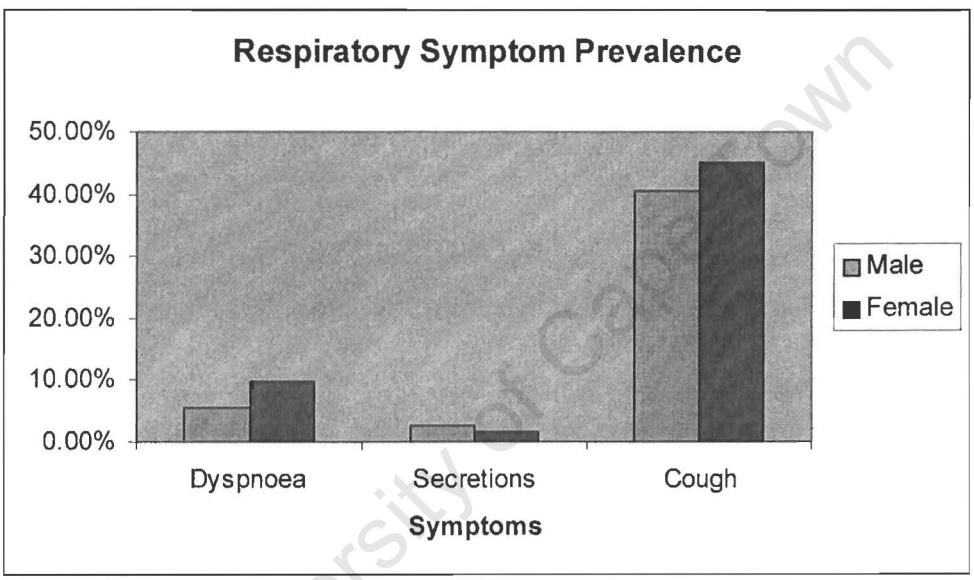
	Total	Percentage	Male	Female	Sum
Dyspnoea	10	8.74%	2	6	8
Secretions *	2	1.94%	1	1	2
Cough	46	44.66%	15	28	43

* "Secretions" refers to increased oropharyngeal and/or upper respiratory tract secretions

- The first two columns of the table represent the results of all respondents. For example, 10 of the respondents said that they experience "dyspnoea" as a symptom. This represents 10 of 103 patients, which is equivalent to 8.74%.
- From this it can be deduced that "cough" (44.66%) is the most prevalent respiratory-related symptom experienced, followed by "headache" (8.74%) and "increased secretions" (1.94%),

- **Figure 6** further splits, by gender, the total number of patients experiencing a particular symptom.

FIGURE 6:



There were no significant gender-related differences found in respiratory symptoms.

4.6 ANALYSIS OF DERMATOLOGICAL SYMPTOMS

Table 5 summarises the results of the analysis of the dermatological symptoms experienced by both males and females.

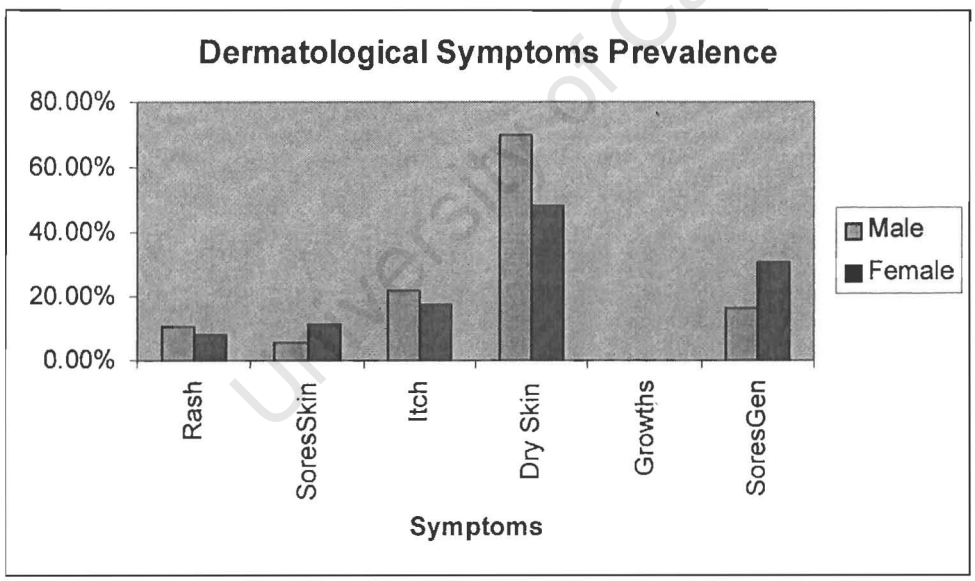
TABLE 5:

	Total	Percentage	Male	Female	Sum
Rash	9	8.74%	4	5	9
Sores on Skin	9	8.74%	2	7	9
Itch	20	19.42%	8	11	19
Dry Skin	58	56.31%	26	30	56
Growths	0	0.00%	0	0	0
Genital Sores	25	24.27%	6	19	25

- From this it can be deduced that "dry skin" (56.31%) is the most prevalent dermatologially-related symptom experienced, followed by "genital sores" (24.27%), "itch" (19.42%).

- **Figure 7** further splits, by gender, the total number of patients experiencing a particular symptom.

FIGURE 7:



- Interestingly, males and females both identified "dry skin" as the major symptom.

A total of 19 (30.65%) female respondents reported genital sores compared to a total of 6 (16.22%) of males. This clearly shows a significant difference between males and females.

4.7 ANALYSIS OF GENERAL SYMPTOMS

Table 6 summarises the results of the analysis of the general symptoms experienced by both males and females.

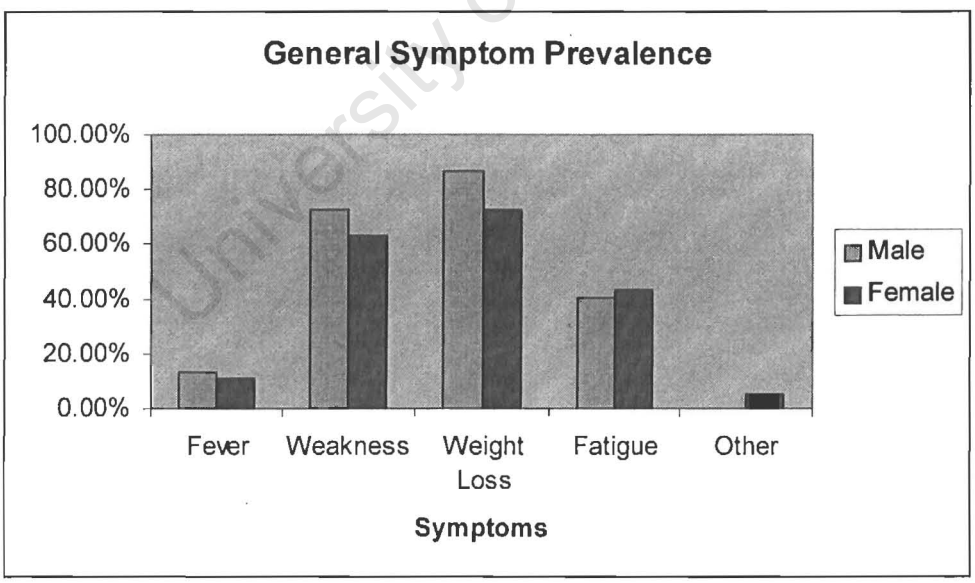
TABLE 6:

	Total	Percentage	Male	Female	Sum
Fever	12	11.65%	5	7	12
Weakness	68	66.02%	27	39	66
Weight Loss	81	78.64%	32	45	77
Fatigue	44	42.72%	15	27	42
Other	3	2.91%	0	3	3

- From this it can be deduced that "loss of weight" (78.64%) is the most prevalent general symptom experienced, followed by "weakness" (66.02%), "fatigue" (42.72%).

- **Figure 8** further splits, by gender, the total number of patients experiencing a particular symptom.

FIGURE 8:



- Interestingly, males and females both identified "weight loss" as the major symptom.

There were no statistically significant gender differences.

4.8 ANALYSIS OF SITES OF PAIN

Table 7 summarises the results of the analysis of the sites of pain experienced by both males and females.

TABLE 7:

	Total	Percentage	Male	Female	Sum
Head	44	42.72%	16	25	41
Mouth	52	50.49%	16	32	48
Throat	41	39.81%	14	24	38
Chest	18	17.48%	3	15	18
Abdomen	13	12.62%	5	8	13
Genitals	13	12.62%	6	6	12
Upper limbs	8	7.77%	2	6	8
Lower Limbs	68	66.02%	24	40	64
Skin	3	2.91%	1	2	3
Muscles	15	14.56%	5	10	15
Rectum	4	3.88%	1	3	4
Back	12	11.65%	3	9	12
Generalised	12	11.65%	8	4	12

- From this it can be deduced that the most common source of pain is lower limbs (66.02%), followed by mouth (50.49%), head (42.72%) and throat (39.81%)
- Table 8 lists the top five sites of pain in order of prevalence:

TABLE 8:

1. Lower limbs
2. Mouth
3. Head
4. Throat
5. Chest

Average number of pains experienced

By summing the number of pains experienced by each individual, and dividing by the number of respondents in the sample, it was concluded that there were a total of 300 pains identified, giving an average of 2.91 pains per patient.

There is no statistically significant difference between males (average 2.92 pains per male patient), and females (average 2.89 pains per female patient).

Pain as worst overall symptom

Patients were asked what their worst overall symptom was. Of all the patients, 34.38% mentioned pain as being their worst overall symptom.

Description of Pain

Respondents were asked to describe their worst pain. A total of 100 respondents described their worst pain . The following list records the five most commonly used descriptive words :

Description of Worst Pain	Number	%
1. Pins and Needles	25	25%
2. Throbbing	21	21%
3. Stabbing	15	15%
4. Burning	13	13%
5. Aching	9	9%

4.9 GENITAL SORES, GENITAL PAIN, DEPRESSION AND ANXIETY

Table 10 shows a combination of the fields "anxiety", "hopelessness", "genital sores" and "genital pain" in the raw data for the purpose of determining whether females' experience was statistically significantly different from males' experience.

Table 10:

	Male	Percentage	Female	Percentage
Anxiety	6	16.22%	15	24.19%
Hopelessness	11	29.73%	20	32.26%
Genital Sores	6	16.22%	19	30.65%
Genital Pain	4	10.81%	9	14.52%

Looking at gender-specific results, it clearly shows that females experience significantly more "anxiety" and genital complications. There does not appear to be a significant difference between males and females with respect to "hopelessness".

4.10 SYMPTOMS AND PAIN IN GENERAL

Average number of symptoms experienced

It was decided to investigate the average number of symptoms experienced by each AIDS patient. In this assessment it was assumed that any form of pain experienced was considered as one symptom, e.g. if a single patient experienced more than one type of pain, this still counted as one symptom.

- There were a total of 942 symptoms identified in the patients sampled, giving an average number of symptoms of 9.14 symptoms per patient.
- There were a total of 338 symptoms identified in the male patients, giving an average number of symptoms experienced by males of 9.13
- There were a total of 564 symptoms identified in the female patients, giving an average number of symptoms experienced by females of 9.10
- The remaining 40 symptoms were attributable to those 4 patients which did not declare their gender (at an average of 10 symptoms per patient)

Overall Ten Most Prevalent Symptoms (including pain)

Of the 103 respondents 101 reported experiencing at least one pain. Pain was clearly the most prevalent of all symptoms.

Table 11 records the ten symptoms in order of prevalence:

TABLE 11 : SYMPTOMS IN ORDER OF PREVALENCE

Symptom	Total	Percentage
1. Pain	101	98%
2. Loss of Weight	81	78.64%
3. Loss of Appetite	73	70.87%
4. Low Mood	72	69.9%
5. Weakness	68	66.02%
6. Dry Skin	58	56.3%
7. Diarrhoea	56	53.4%
8. Nausea and Vomiting	46	44.66%
9. Cough	46	44.66%
10. Fatigue	44	42.72%

CHAPTER 5 :DISCUSSION, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

5.1 DISCUSSION

5.1.1 ART In The Developing World

Since the advent of ART in the mid- 1990s, the number of deaths per year from AIDS has dropped dramatically in the developed world. With excellent adherence to ART, HIV no longer produces a rapidly fatal illness and AIDS is seen as a chronic manageable disease. ART reduces the viral load in the blood (in ideal cases to below the detectable limit). This allows some recovery of the immune system and a reduction in morbidity and morality owing to HIV disease. (46)

However, this dramatic decline in HIV/AIDS has not occurred in the resource-poor countries of Africa and the Asia Pacific region. Preventative programs are rudimentary and access to ART, antibiotics and anti-neoplastics is extremely limited. In the developing world, most infected persons are destined to die of AIDS, and yet, the focus of care has shifted away from exploration of symptoms and quality of life issues. (24)

It is of interest to note that despite the successes of antiretroviral treatment, new diagnoses of HIV infection have not decreased. (16)

Sub-Saharan Africa has the highest incidence of HIV/AIDS in the world (25) and health care workers are faced with an overwhelming number of patients with advanced AIDS. SA has the worst and fastest growing HIV/AIDS epidemic in the world. (28)

In SA, AIDS is the leading cause of death with an estimated 4.7 million people living with HIV/AIDS. Half of all infected adults are infected prior to 25 years of age. The percentage of adults (age 15-49) living with

HIV/AIDS is 20.1% (25). In this study sample of young black Sowetans only 3.88% had ever had access to ART.

It is estimated that only approximately 30 000 of South Africa's 4.7 million HIV+ individuals receive ART. (28) The vast majority of SA AIDS patients do not currently have access to ART.

Although Palliative Care is appropriate for all patients with HIV/AIDS at all stages (16), Palliative Care has an even greater role to play in countries where drugs are unavailable or unaffordable to most (26) and especially so in Sub-Saharan Africa where AIDS has reached pandemic proportions.

5.1.2 Patient Characteristics

Age:

In SA young people are considered a particularly vulnerable group. The mean age of respondents in the study is 34.5 years with a standard deviation of 8.8 years. The youngest respondent taking part in the study was 22 years. In a comparative study done in the USA, the average age of patients on a Palliative Care program was 38.6. (27)

It is estimated that there are some 18 million South Africans under the age of 20, accounting for approximately 44% of the total population. Between 1998 and 1999, there was a 65% increase in the prevalence of HIV in 14-24 year olds (30).

SA is at the epicentre of the global HIV/AIDS epidemic and this research reinforces the fact that without access to ART, patients will present with advanced stage AIDS from age 20 onwards.

Young people in SA today are living in a period of westernisation and modernisation of the African cultures, resulting in a vacuum where clearly defined roles and values that adolescents can emulate are lacking. At the same time, due to the economic crisis and poverty, adolescents have been affected in spheres such as education and the meeting of their basic needs. (30).

The relatively young age of most persons living with HIV/AIDS is often associated with fewer housing and financial resources, insufficient preparation for a rapid, debilitating illness, fewer culturally approved spiritual rituals or practices and less social support from the community. (49)

The Nelson Mandela/HSRC study of HIV/AIDS 2002 showed that sexual experience amongst youth was significantly higher in urban informal areas than in other types of localities. Amongst sexually active 15-24 year olds in South Africa, the median age of sexual debut was 16 years. (31)

In reality, young people with AIDS have little support, high stress levels leading to high levels of depression and mood disorders. (49)

Gender:

The main mode of transmission of HIV is heterosexual, and women represent 2,7 million of the 4.7 million South African adults with HIV/AIDS (25). Up to 8 times more adolescent girls than boys are living with the disease. (30)

The mean age of a female respondent is 33.9 years, whereas the mean age of a male respondent is 38.9 years. Females are on average 4.4 years younger than males.

Findings of this research are in keeping with the fact that not only are women becoming infected at a younger age, but there are also significantly more women who are living with HIV/AIDS in SA compared to men. (25)

In the study sample of Soweto patients, male patients comprised 37.37% of the sample and female patients 62.63%.

Reasons that more women are dying of AIDS and at a younger age, are manifold. There are clearly discernible patterns that emerge and shed light on the African pandemic. There is a significant body of well-researched and documented Social Science studies which include reasons such as :

- Early first sexual encounter; (30) (35)
- Premarital and extramarital sexual relations; (10)

- Female silence and helplessness: women have a lower status in society at large and in sexual relationships in particular; (30)
- The STI epidemic;
- Resistance, including violence as a reaction to requests for condom usage in the SA culture; (33)
- Poverty and a need to exchange sex (transactional sex) to meet the basic needs of their family members and themselves; (32) (33) (10)
- Male dominance; (10)
- Gender violence : rape and coercion through violence, is extremely common in our society today; (25)
- Women are expected to be passive in their sexual relationships resulting in sexual sub-ordination; (10)
- Economic disempowerment of women; (33) (34)
- Poverty; (32)
- Biological vulnerability: women have a larger mucosal surface exposed during intercourse and semen has a far higher concentration of HIV than vaginal fluid;
- Women are epidemiologically vulnerable: women tend to marry and have sex with older men who tend to be more heavily infected than younger males;
- Some South Africans still believe in polygamy and this has proven to speed up the transmission of HIV. (10)
- It is also common in many societies for older men to marry younger girls, and these men have previously been in other relationships. (30)

Many of the female patients at Soweto Hospice are mothers caring for babies, toddlers and young children, some of whom will also test positive for HIV or be ill with AIDS.

There is a great deal of sorrow, anxiety and stress resulting firstly, from knowing that they will not see their children grow up and secondly, around decisions about guardianship. (37) In this study, female respondents had significantly more anxiety than males. It can only be speculated that the above-mentioned reasons contributed to this distressing symptom.

Women with HIV/AIDS often have a very different clinical course from that of men. Gynaecological manifestations of HIV are common in women.

(38) In this study there is a statistically significant difference between male and female respondents regarding genital pain and genital sores.

It is therefore essential, when providing Palliative Care to these young women, to be sensitive to the often painful and complicated issues relating to young women and girls in the contemporary South African context.

As the number of women becoming infected rises worldwide, we need to become familiar with the specific and unique issues and needs of this community. (38)

5.1.3 Symptomatotolgy

The Palliative Care of a patient with advanced AIDS includes active control and management of opportunistic infections and malignancies as well as meticulous control of pain and symptoms.

The data offers some insights into the sites of pain and symptom complexes experienced by SA AIDS patients who do not have access to ART.

A very different clinical picture is seen in AIDS in the developed world, where AIDS is now viewed as a chronic manageable disease.

In SA, as in most developing economies, drugs are expensive or simply unavailable and HIV disease progresses unchecked with high morbidity and mortality. (39)

It is therefore extremely important to be aware of the most prevalent and burdensome pain and symptoms experienced, in order to adequately and actively manage our patients with AIDS.

Even if ART becomes more available to all patients in developing countries, there will be problems due to lack of education, adherence and the development of resistance. All health care workers need to focus attention on the meticulous control of the pain and many symptoms associated with advanced AIDS.

In a study done by Fontaine et al it was found that physician recognition of symptoms experienced by HIV patients was low. Symptoms that could be alleviated by specific treatment such as diarrhoea, nausea and vomiting were not recognised and therefore attention was not paid to these potentially treatable conditions. (19)

This study highlights the most prevalent symptoms experienced by a patient with advanced AIDS in order to facilitate improved symptom recognition by health care workers. More attentive history taking and systematic clinical examination are required for appropriate symptom management.

Based on the findings in this research, the author plans to develop Palliative Care protocols for the management of each symptom using medications available in resource-poor settings, and strategies to improve the quality of life of patients.

Symptom control should not be neglected, or only reserved for patients in severe end stage disease; it should be part of the management of all patients at all stage of HIV/AIDS. Although symptom control has been advocated mainly by Palliative Care practitioners it should be an essential component of patient care at all stages of the disease. (19)

Different studies in the literature report varying symptom prevalence figures, depending on setting and stage of disease (27) (18) In the Soweto study, the mean number of symptoms experienced was 9.

In this study the most common symptoms in order of prevalence are loss of weight (78.64%), loss of appetite (70.87%), low mood (69.9%), weakness (66.02%), dry skin (56.3%), diarrhoea (53.4%), nausea and vomiting and cough (44.66%), fatigue (42.7%) and abdominal cramps (41.75%)

The large number of symptoms and high level of distress experienced by a patient with AIDS can sometimes present an overwhelming scenario to the health care practitioner. The common clinical spectrum of AIDS is broad, covering a range of opportunistic infections, malignancies and neuropsychiatric disturbances. The morbidity of symptoms related to these conditions is high. While the medical care of AIDS patients may seem

complex, their management is within the capacity of all experienced Palliative Care programs. (40)

Most qualified doctors in SA have received little or no formal training in HIV/AIDS care or Palliative Care. Suddenly there are too many patients and the specialist clinics cannot cope and the primary care level is faced with dealing with this epidemic without clear guidelines. This has resulted in sub-optimal and haphazard care. The biggest barrier to care is the anxiety doctors feel when dealing with something they have not been trained it, with a background of overwhelming workloads. (50)

Decisions about management must be based on knowledge and understanding of current information, investigation and treatment of a myriad of infections and/or malignancies as well as that of symptoms and pain. (41)

Central Nervous System-related Symptoms:

In this study, the symptoms related to the Central Nervous System showed that in both males and females "low mood" (69.9%) was the most prevalent symptom, followed by "hopelessness" (31.07%), "loss of memory" (30.10%) and "anxiety" (20.39%).

A comparison of these findings against data from other studies, showed that CNS symptoms of "low mood", "anxiety", "worry", "depression", and "sadness" are consistently reported as the most frequently reported symptoms. (19) (27)

Vogl	: Worry 86%
et al	Sadness 82%
Fontaine	: Anxiety 64%
et al	Depression/sadness 63%

There is a difference seen in studies done on cancer patients where "pain", "easy fatigue" and "anorexia" were consistently among the 10 most prevalent symptoms associated with cancer at all sites. (42)

The reasons that patients with AIDS experience such a high level of CNS symptoms is related to the neurological and neuropsychiatrc diseases related to HIV/AIDS, including various opportunistic infections, tumours

and direct effects of HIV. In addition, these young patients describe a sense of isolation, lack of support and security and are often faced with young children and ill partners against a background of poverty, poor education and lack of understanding.

With the political, cultural and economic turmoil in SA and the emergence of a disempowered and demoralised adult society, it is understandable that when faced with HIV/AIDS, there is resultant hopelessness, fear and anxiety.

The study showed that female patients experienced significantly more anxiety than men. Females experienced anxiety in 24% of respondents whereas males in 16% of respondents.

Reasons for the high level of anxiety in female patients have been discussed earlier, and include concern for young children, babies and partners, guardianship of children, and issues relating to feeding and housing of family.

The economic disempowerment and the vulnerability of women, psychological and social dependence on men are also a factor contributing to the high level of anxiety in these patients. (30)

Gastrointestinal tract-related Symptoms:

Almost all HIV positive patients have GIT involvement during the course of their illness. (46)

The analysis of GIT symptoms reveals that "loss of appetite" (70%), is the most prevalent symptom followed by "diarrhoea" (53%), "vomiting" (45%) and "abdominal cramps" (42%) are also very common and will be discussed later.

It is well known that anorexia and cachexia are very common in advanced disease as a direct result of HIV infection, as well as resulting from malignancies and infections. (26)

Diarrhoea is a common problem in AIDS in areas where there is limited access to ART and is a result of a myriad of opportunistic infections, such as Salmonella, Mycobaterium Avium Complex and Cryptosporidium,as well as the HIV virus itself. Specific anti-microbial treatment, if available, is often disappointing. Abdominal cramps are also often associated with diarrhoea, and this is confirmed in the study where 42% of respondents complained of "abdominal cramps" and 53% of "diarrhoea".

There is a need for health care workers in the field to be aware of the palliative management of diarrhoea and cramping which has a very high level of success, in spite of underlying infections which are often untreatable. Symptomatic control of diarrhoea is important not only for palliation, but also to facilitate the absorption of active treatment given orally. (43) The use of codeine, low dose morphine and high dose regular loperamide is common in Palliative Care.

It is interesting to note that in the study population, constipation is rare (6%). Studies on patients using ART show that constipation is a more common symptom. (27)

Nausea and vomiting are worrisome symptoms greatly affecting quality of life. 45% of the respondents experienced "nausea" and "vomiting". Possible causes include: oropharyngeal candidiasis, certain drugs, fever, systemic infections, tumours, diarrhoea, hepatobiliary disease and anxiety. (45) (46)

Fortunately, the palliative management of nausea and vomiting is very effective and knowledge of the correct antiemetic for the different sites and causes of nausea is essential for all doctors and nurses working with patients with AIDS. For example, low dose haloperidol is effective in managing nausea related to drugs, chemicals and toxins.

Respiratory System-related Symptoms:

Pulmonary disease is a major cause of illness and death in patients with HIV infection. At post mortem, the lungs are affected in about 90% of cases. (46)

The most prevalent respiratory symptom documented in this study was 'cough' experienced by 45% of respondents. The possible causes of cough in this population include infections such as bacterial pneumonia, Pulmonary Tuberculosis, Pneumocystis Carinii Pneumonia, fungal infections and Cytomegalovirus, as well as malignancies such as Kaposi's Sarcoma and Non-Hodgkin's Lymphoma (44), (46).

Coughing is a distressing symptom and often aggravates pain and nausea. The control of cough, regardless of aetiology, using Palliative Care principles, is effective and makes an important contribution to improving the quality of life of our patients. An example of the Palliative management of cough, is the use of low dose morphine elixir which is both safe and effective.

Dermatologically-related Symptoms:

AIDS patients frequently present with many different dermatological conditions, such as Seborrhoeic dermatitis, fungal infections, ichthyosis, scabies, molluscum contagiosum, warts, itchy papules, Kaposi's Sarcoma, and varicella zoster. (46)

In the study population, the most prevalent dermatological symptom was 'dry skin' (56%). Dry skin is a debilitating condition resulting in scratching, excoriation, irritability, restlessness and insomnia. Excellent nursing and meticulous attention to skin care (with or without the use of oral medication) is the mainstay of management of this symptom. The second most prevalent dermatological symptom was 'itch' (19%) which often accompanies a dry skin and is a challenging symptom to treat. Itching could also be a result of disseminated scabies or fungal infections. Itching can be managed with topical and systemic medication.

General Symptoms:

Symptoms of "weakness" (66%), "loss of weight" (79%) and "fatigue" (43%), were reported by the respondents and have been well-documented in published literature on AIDS symptomatology. (19) (40)

Referrals to Hospice often come late in the illness trajectory and some of the symptoms such as weakness and fatigue or weight loss are difficult to treat or reverse compared to symptoms such as pain and cough. (47). Referrals to Palliative Care services or knowledge and application of Palliative Care Principles (including nutritional care) earlier in the course of illness are needed for more effective management of these challenging symptoms.

5.1.4 AIDS-Related Pain

The problem of pain in AIDS, along with its widespread under-treatment, has rapidly emerged as an important clinical issue in the care of patients with HIV disease. (20)

People with HIV disease often have multiple pains occurring concurrently and the pain has profound effect on their quality of life.

Of the 103 respondents, 98% experienced pain and 34% mentioned pain as the worst overall symptom.

Under-treatment of HIV-related pain is problematic in several countries. Current understanding of the management of pain in patients with HIV was developed in the pre-ART era of the late 1980s and early 1990s (24) In SA, where patients usually do not have access to ART and often do not have the benefit of rigorous control of opportunistic infections and AIDS-related cancers, the control of pain is a great challenge.

The study was aimed at determining prevalence of pain by site. Deductions as to the cause and type of each pain based on site would then guide the development of guidelines and protocols for the management of AIDS-related pain.

Although more detailed research needs to be done on AIDS-related pain in SA (relating to pain severity, type and cause) this study simply aims to focus attention on the most prevalent anatomical sites of pain.

A study by Glare (2001) on patients with AIDS, showed that on average, patients had pain occurring in three different sites concurrently with 33% of patients experiencing pain in four or more sites. (24)

This study shows a similar trend with the average number of pains occurring in 2.91 different sites at one time. The five most common sites are:

1. Lower limbs	66%
2. Mouth	50.49%
3. Head	42.72%
4. Throat	39.81%
5. Chest	17.48%

A study by Kemp (1995) also demonstrated that most patients with AIDS have pain at more than one site and the most common sites are lower extremities, abdominal, oral cavity, oesophagus, skin, peri-rectal area, chest, joints, muscles and headache. (17) This is in the pre-ART era and is in keeping with the findings of this study.

It is therefore essential for effective pain control that the Health Care Professional performs a thorough pain assessment including pain history and physical examination, and that each individual pain is documented and given a rating of severity. Control of pain, using the WHO analgesic ladder with non-opioids, opioids and adjuvant analgesics as well as non-pharmacological therapy is required.

Unfortunately, AIDS carers tend to underestimate patients' pain, admitting a lack of knowledge about analgesia and a reluctance to prescribe opioids. (18) Estimates of the extent of under-treatment of pain in AIDS vary but have exceeded 80% amongst AIDS patients. (20)

Barriers to pain management in SA include lack of knowledge about HIV/AIDS, Palliative Care and pain control, as well as lack of access to essential analgesics or pain management specialists. Unfounded fears regarding the use of potentially addictive drugs contribute to the problem.

The use of ART is one of the most effective means to control pain in AIDS; however, even patients who have received ART, continue to experience pain during the final stages of their lives. (24)

Intensive educational programs need to be developed to provide education on the knowledge, skills and attitudes necessary for the effective management of pain in patients with AIDS.

Only with aggressive interventions on both clinical and research fronts will the problem of pain in AIDS be adequately resolved. (20)

Lower Limb Pain:

Both male and female respondents identified "lower limbs" as the major source of pain (65%). Respondents described their pain in words such as "burning" (13%), "pins and needles" (25%) and "stabbing" (15%), suggesting pain of a neuropathic nature. This pain is most likely the result of a peripheral sensory neuropathy related to HIV. HIV related neuropathy presents with painful dysaesthesias and numbness in a "glove and stocking" distribution (46).

A similar study on patients with AIDS before the ART era confirms that lower limb pain is the most common pain experienced. (17)

A comparison to a study done in the ART era shows upper gastrointestinal tract infections to be the main origin of the pain, although pain in the extremities is still listed amongst the three most common pain localisations. (18)

A painful peripheral sensory neuropathy is most likely to be caused by HIV itself in the study population, although other possible causes such as diabetes, post herpetic neuralgia, vitamin deficiency and alcohol abuse need to be considered. It is rare for a patient in Soweto to have been on antiretroviral drugs and so this is seldom a contributing cause of peripheral neuropathy.

The common pain syndromes in HIV/AIDS such as neuropathic pain, abdominal pain and headache are considered to be 'difficult pain problems' when they occur in people with cancer.

It has been demonstrated that pain in untreated HIV disease has many similarities to cancer pain, and the treatment of both is based on the WHO 3-Step analgesic ladder (18).

Both cancer and AIDS related pains are often multiple, occurring concurrently and are progressive (24). However the use of adjuvant analgesics such as the antidepressants, anticonvulsants, antispasmodics and corticosteroids are often necessary in addition to non-opioids and opioids in the management of complicated AIDS related pain syndromes - such as neuropathic pain.

Neuropathic pain eg. Peripheral Neuropathy and Post herpetic neuralgia, is well known to be a difficult and complex pain to treat and health care workers need to be aware of the various non-opioid, opioid and adjuvant analgesics available to treat neuropathic pain, as well as the anaesthetic techniques and physical therapies that apply.

Oropharyngeal Pain:

Oropharyngeal pain is known to be an important site of pain in patients with AIDS. (17) (18) "Mouth" (50%) and "throat" (40%) pain were reported in this study in the top five most prevalent sites of pain.

In a study by Cole (1991), virtually all patients referred to a Palliative Care service had oral and oesophageal candidiasis. (40)

In South Africa, oral pain is common and the most frequent causes include oral candidiasis, apthous ulceration, herpes simplex virus, gingival and periodontal disease, salivary gland disease and Kaposi's Sarcoma. (44) (46)

Increased knowledge of the palliative management of a painful mouth and odynophagia would improve both the quality of life and nutritional status of

these patients. An awareness of the many different ways to palliatively manage HIV-related oral pain using topical and systemic therapy, would equip SA doctors to deal with this distressing and compromising sympton.

Oesophageal ulceration, tumours and infection often result in severe burning retrosternal chest pain and odynophagia. In a study by Frich (2000), upper gastrointestinal infections were the main origin for their patients' pain causing burning and scorching pain. (18)

It can be speculated that pain referred to from the sites of both 'throat' and 'chest' in this study could well be referring to pain arising from the oesophagus. Treatment of the underlying conditon may result in more effective pain relief than general measures alone, although the use of the WHO analgesic ladder works well with few exceptions. Strong opioids have been shown to be effective and well-tolerated in short term studies. (20)

Chest Pain:

Chest pain accounts for 17% of pains in the study population although there would be some overlap with throat/oesophageal pain. A large proportion of South African AIDS patients have Pulmonary Tuberculosis, Pneumocystis Carinii Pneumonia and other respiratory infections. TB is the most common opportunistic infection in SA and reports of multidrug-resistant TB are increasing daily. Other possible causes of chest pain in the study population could include varicella zoster infections (shingles) and post herpetic neuralgia, TB pericarditis and tumours such as Kaposi's Sarcoma and Non Hodgkins Lymphoma. (46)

Again the palliative management approach, with or without ART, would be to actively treat infections and tumours where possible and control pain and associated symptoms such as dyspnoea, cough or increased respiratory secretions.

Headache:

Headaches are very prevalent amongst patients with advanced AIDS. 43% of the respondents reported "headaches".

There are many documented causes of headache in a patient with AIDS from intracranial infections and tumours to adverse effects of anti-retrovirals, sinusitis, migraine, systemic infection and tension headaches. (46)

HIV meningo-encephalitis, neurosyphilis, TB meningitis and cryptococcal meningitis are serious but manageable conditions causing headaches that need active treatment as well as effective pain control.

Genital Pain:

It is interesting to note that female respondents experienced a statistically significantly greater amount of "genital pain" than males. Of the respondents, 16% reporting genital pain were female compared to 10% of males. Females also reported statistically significant 'genital sores' (31%) than males (16%).

These findings reflect the fact that in SA, women are more vulnerable to HIV/AIDS due to an epidemic of STIs (30)

Again, genital pain is not a simple pain to treat, and requires a thorough assessment and knowledge of the use of pharmacological and non-pharmacological techniques to control pain.

There is still a great need for more research if we are to fully understand the specifics of this disease in females. Little is known about the needs and issues of women with HIV/AIDS at the end stages of life. (30)

Other pains, such as abdominal pain with or without cramping, muscular pain, backache and generalised body pains need to be recognised and treated in order to improve the quality of life of our patients.

The study by Frich et al (2000) showed a statistically significant increase in the number of disturbing pain localisations during the last 6 months before

death. (18) This study confirms the literature that pain is an extremely common symptom in end stage AIDS. Although pain in patients with advanced AIDS has many similarities with cancer pain, there are also important differences.

There are many challenges to managing AIDS-related pain and it is important to take into account polypharmacy, heightened sensitivity to drug side effects, psychological co-morbidity, drug interactions, AIDS dementia complex and lack of access to analgesics and pain specialist clinics.

5.1.5 Overall Review of Pain and Symptoms

The list below documents the 10 overall most prevalent symptoms experienced by patients in this study:

Pain	98%
Loss of weight	79%
Loss of appetite	70%
Low mood	70%
Weakness	66%
Dry skin	56%
Diarrhoea	53%
Nausea & vomiting	45%
Cough	45%
Fatigue	43%

Many of the above, including pain, low mood, dry skin, diarrhoea and abdominal cramps, nausea and vomiting and cough, can be effectively managed using Palliative Care treatment principles.

Symptoms such as loss of weight, fatigue, weakness and loss of appetite are often seen as more difficult to control, but they could be the result of reversible conditions such as oropharyngeal candidiasis. Any reversible underlying conditions should always be treated. It is in keeping with the Hospice philosophy that there is always something that can be done (no matter how small) to help patients with difficult irreversible symptoms, regardless of prognosis.

The patients in this study are patients with advanced WHO Stage 4 AIDS who are on a Hospice program. Yet many symptoms experienced by a patient at this late stage are present in earlier stages of the disease. Table 9 shows a comparison with a study done on mixed stage HIV disease in 1999 by Fontaine et al, and shows many similarities. (19)

TABLE 9

Symptom	Soweto End Stage Disease Stage 4 WHO	Fontain et al Mixed Stage Disease
Depression/sadness/low mood	70%	63%
Loss of weight	79%	60%
Cough	45%	57%
Nausea and vomiting	45%	48%
Diarrhoea	53%	45%
Itch	19%	28%
Fatigue	43%	77%
Anxiety	20%	64%

It is possible that fatigue is less obvious or problematic to a patient who has WHO stage 4 disease (bed-bound for more than 50% of the day) compared to a patient who is ambulant, mobile and possibly frustrated with weakness and tiredness.

Anxiety is less prevalent in the Soweto study and may be related to the late stage of diagnosis where patients are often less cognitively aware and indifferent to their illness and surroundings. (40)

Multiple symptoms can occur at any stage of HIV infection, although the incidence and severity increases with advanced disease. (27) The mean

number of symptoms (including pain) experienced by patients in the Soweto study was 9 per patient. In a study by Vogl et al on 504 out-patients with AIDS in New York, individuals reported a mean of 17 different symptoms (27)

Reasons for this discrepancy might include the fact that the patients in the Soweto study were extremely ill and often in the last days of life, perhaps reducing the ability to report in any great detail how they felt. It is possible that the lower level of education in the Soweto group compared to the American group would affect the ability to describe a condition in as much detail.

5.2 Limitations of the Study

1. The questionnaires were completed by Professional Nurses on behalf of the patients using English, Zulu or South Sotho, depending on the patients' preference. Although the nurses received training in interview technique and the use of the questionnaire, there were five different people interviewing which would introduce bias to the results. It is possible that the interviewers' interpretation of pain and distressing symptoms was innacurate.
2. For the purpose of the study, a sample size of 103 respondents was used. The sample was appropriate within the scope of this study; however, due to its small size, its generalisability was limited. Because the sample size is small, it was felt that any conclusions drawn from a correlational analysis would be spurious.
3. The sample of 103 patients was taken from a total of 440 AIDS patients registered at Soweto Hospice between May, 2002 and February, 2003. The sample of 103 respondents was biased, in that it was a voluntary sample of patients willing and alert enough to take part. The study did not therefore elicit symptoms from patients who were too ill, confused, or demented. The results therefore do not give a true reflection of the overall Palliative Care patient population at Soweto Hospice.
4. A comparison of difference in gender of respondents and non-respondents showed that this study population was not a properly representative sample. Although it is known that a higher percentage of females are affected by HIV/AIDS in South Africa, the percentage of

females (63%) to males (37%) in the study population was skewed towards females, compared to the non-respondents, females (54%) to males (46%). The size of the study sample is too small to be able to comment on the statistical significance of this difference.

5. This study did not access severity of pain or symptoms and future studies will need to address these measurements.
6. The study was limited to adult patients with advanced AIDS in a Hospice setting and may not be generalised to hospitals or other settings.

In spite of its shortcomings, this study is one of the first to examine the pain and symptoms of a patient with advanced AIDS in urban SA.

5.3 Recommendations : The Way Forward

There is very little research on end-of-life issues in HIV/AIDS in SA. Because of the focus on the social, political and economic arguments around the use of ART, health care workers have neglected to deal with the real life issues of thousands upon thousands of patients with AIDS-related pain and symptoms.

Regardless of whether anti-retroviral drugs become available to all South Africans with HIV/AIDS, there will always be a need for Palliative Care. In fact, ART is simply a very effective form of Palliative Care.

It is recommended therefore, to continue building this area of science that focuses mainly on the patient and not exclusively on the disease.

Further research on the pain and symptoms experienced by patients with HIV/AIDS will provide the best care for these patients as well as the data that policy making organisations need to make informed decisions.

More study is needed to explore issues around genital pain and anxiety which are statistically more prevalent among Sowetan women. Specifics of this disease in female patients, and the many issues that arise, need to be more fully investigated.

This research suggests several areas in which professional education may be beneficial. Doctors, nurses and health care workers as well as undergraduate medical and nursing students need to be made aware of the

role of Palliative Care in the management of all patients at any stage of HIV disease.

Increased knowledge of basic pain control and the management of difficult pain syndromes is needed through education and training. Awareness of the many effective symptom control protocols and guidelines used in Palliative Care will help doctors and health care workers feel better equipped to deal with the overwhelming numbers of patients.

Future research on pain and symptoms experienced by a patient with AIDS should include severity-rating scores. Data on severity is particularly relevant to clinical practice, but is to date, quite limited.

There is great potential for more research regarding the spiritual and psychosocial issues around disease, death and dying in this group of relatively young adults.

A large percentage of patients were excluded from the project because of AIDS-related dementia, confusion or delirium. Further research into this particular group of patients is needed to achieve a more comprehensive knowledge base and awareness of the specific needs and concerns of these patients.

5.4 Conclusions

In order to deliver high quality end-of-life care for patients with AIDS in SA, it is necessary to determine the best approaches to control pain and symptoms in these patients. This study identified the most prevalent symptoms and sites of pain experienced by a patient with advanced AIDS in an urban setting.

This study on patients with AIDS in Soweto revealed that the mean age of a female patient is younger than a male patient and that females are experiencing statistically significantly more anxiety and genitally-related sores and pain. There is also a higher percentage of female to male patients.

The study shows that the five most common sites of pain in order of prevalence are lower limb pain, mouth pain, headache, throat pain and chest pain.

It reveals that the ten most common symptoms in a patient with advanced AIDS are pain, loss of weight, loss of appetite, low mood, weakness, dry skin, diarrhoea, nausea and vomiting and fatigue.

The average numbers of pain experienced by a patient is 2.91. Pain was the most prevalent overall symptom.

The study showed that the vast majority of patients did not have access to ART and this fact alone highlights the necessity for this type of research.

The results of this study will be an essential guide to the development of protocols of care that would be applicable in a developing country where access to ART is limited.

The core focus of care of patients with advanced AIDS should be placed on symptom relief along with active treatment of underlying infections. (18)

Caring for patients with AIDS in a Hospice program presents numerous challenges. Many people living with HIV/AIDS are also dealing with other stressful problems such as unemployment, alcohol dependency, child support and infected children. The holistic care of a patient with AIDS should go beyond pain and symptom control to include social, emotional and spiritual support.

Communication between all people involved in the multidisciplinary treatment of these patients is essential. Common goals should be identified and general approaches agreed on amongst the physicians, nurses, therapists, clergy and volunteers. (29)

Health Care Workers should focus on the patient rather than on the disease and should not neglect the basic clinical information that can be elicited through attentive listening and thorough examination. Attention to detail is the true mark of a professional.

In the Palliative Care of late stage AIDS special difficulties arise in alleviating pain and suffering. Many people mistakenly believe that Palliative Care, with its low tech nature, comes into play only after medicine has exhausted all the skills and technologies that might bring about a cure. However, Palliative Care and medical research and technology are not mutually exclusive. (47)

"The key to extending the provision of Palliative Care is education and the sharing of knowledge" Mari Lloyd Williams

It is hoped that the results of this study will be used in improving Palliative Care education around HIV/AIDS by identifying common causes of distress. It is essential that training opportunities in Palliative Care parallel the growth in Palliative Care services.

Effective Palliative Care of a patient with AIDS involves the active treatment of opportunistic infections, cancers and reversible conditions as well as the palliation of symptoms and pain. The use of anti-retroviral therapy is the best possible means of palliation in AIDS but is as yet unavailable to most South Africans.

During the last days of a person's life, therapies that provide comfort and support are usually more important, although disease-specific therapies may continue until death.

It is hoped that through the results of this study, there will be an improvement of programs aimed at systematic pain and symptom recognition and treatment; further, that clinical guidelines and protocols will be developed, and that it will stimulate more research into this "lost chapter" in the management of HIV/AIDS.

"Knowing is not enough; we must apply.
Willing is not enough; we must do."
GOETHE

DEFINITION OF TERMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
CNS	Central Nervous System
GIT	Gastrointestinal Tract
HIV	Human Immunodeficiency Virus
PALLIATIVE CARE	Palliative Care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO definition of Palliative Care Aug 2002)
SA	South Africa
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Program on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

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ANNEXURE A:

QUESTIONNAIRE

Study Number			
AGE ..... Years			
SEX M ☐ F ☐			
Date of first visit ..... Date of admission to IPU ..... Date of discharge ..... Date of death			
SYMPTOMS : Please tick relevant symptoms experienced by patient :			
CNS			
Anxiety		Low mood	
Hopelessness		Fitting	
Blurred vision		Disorientation	
Loss of memory		Stiff neck	
Dizziness			
Loss of sensation			
GIT			
Nausea and Vomiting		Diarrhoea	
Abdominal cramps		Bloating	
Hiccups		Loss of appetite	
Constipation			
Respiratory			
Shortness of breath		Cough	
Increased secretions			
Skin			
Rash		Dry skin	
Sores on skin		Growths	
Itch		Sores on genitals	

General			
Fever		Loss of weight	
Weakness		Fatigue	
Other			

PAIN			
Headache		Upper limbs	
Mouth		Lower limbs	
Throat		Skin	
Chest		Muscles	
Abdomen		Rectum	
Genitals		Generalised	
Backache			

WHICH PAIN IS THE WORST?.....

HOW WOULD YOU DESCRIBE YOUR WORST PAIN?			
Throbbing		Pins & needles	
Stabbing		Radiating	
Burning		Stinging	
Tingling		Cutting	
Aching		Nagging	
Shooting		Crushing	
Dull		Sharp	
Other		Gnawing	

Have you had access to Anti-retroviral Therapy? Yes ☐ No ☐

Which symptom bothers you the most?.....

(ZULU and SOTHO interpretation of words available.)

ANNEXURE B: Consent Form

CENTRE FOR PALLIATIVE LEARNING
HOSPICE WITWATERSRAND

Research on identification of the most prevalent symptoms experienced by AIDS patients at Hospice Soweto.

CONSENT FORM

I, ..., have read the Information Sheet and understand the contents. I have received acceptable answers to my questions and I willingly consent to participate in these studies. I have been given a copy of the Information Sheet for my records.

Signed ..... Date .....

Witness ..... Date .....

This consent form is also available in Zulu and Sotho.

ZULU

Ukuphenyisisa ngezimpawu ezibonakala kubantu abaphethwe ingculazi (AIDS) e Hospice e Soweto.

CONSENT FORM

Mina, ... ngifundile imininingwane ebhaliwe kanti futhi ngiyayizwisisa. Ngithole izimpendulo ezigculisayo mayelana nemibuzo yami kanti futhi ngizimisele ukuhambisana nalezi zifundo. Nginikwe ifomu yezaziso "Information Sheet" mayelana nomlando wami.

Signed ..... Date .....

Ufakazi ..... Date .....

SOUTHERN SOTHO

CONSENT FORM

Nna, ... badile tsibiso go tswa letlakaleng, ka utlwisisa di ka gare. Ke amogetse dikarabo go tswa kipotsong tsa ka. Gape ke ikemiseditse go nka karolo dithutong tsena. Ke filwe tsibiso ya rekoto tsame.

Signed ..... Date .....

Witness ..... Date .....

ANNEXURE C : Patient Information Form

CENTRE
FOR
PALLIATIVE LEARNING

SUBJECT INFORMATION SHEET

RESEARCH INTO SYMPTOMS RELATED TO AIDS

Why are we doing this research?
The number of Patients with HIV/AIDS is increasing rapidly in southern Africa.

'AIDS' stands for : 'Acquired Immune Deficiency Syndrome' and is caused by a germ called HIV. 'HIV' stands for 'Human Immunodeficiency Virus'. HIV weakens the body's immune system so that the body is unable to fight infection. The immune system gets weaker and weaker causing the Patient to become increasingly ill.

The illness AIDS can cause a lot of suffering from pain and many different symptoms. There has been a lot of research into trying to find a cure for HIV/AIDS. However, until a cure is found, Patients are still suffering.

This research is focusing on the symptoms that a Patient with AIDS experiences.

What is the aim of these studies?
Hospice aims to identify the most common symptoms that a Patient with AIDS experiences. This will lead to working out the best way to manage these symptoms to ensure that our patients are as comfortable as possible, and do not suffer.

What will we ask you to do?
All we ask of you is that you answer some questions for a questionnaire. A Nursing Sister will fill in the questionnaire for you. You will not need to write yourself.

Discomfort and risks

The questionnaire is anonymous. Your name or Hospice file number will not be on the form. We will need at most, half an hour of your time.

Who will benefit from this research?

It is hoped that this research will greatly improve the way Hospice staff manages the symptoms of Patients with AIDS.

We also hope that other doctors and nurses will be able to identify and treat AIDS-related symptoms by using the guidelines that are developed from this research. Other people suffering from AIDS will benefit from this work.

Who will know the results of this research?

The results of the research will be published in the scientific literature. However, your name will not be mentioned and all your records will be kept confidential.

Whom may I contact for more information?

Dr D A Norval
Hospice Centre for Palliative Learning
Hospice Witwatersrand
50 2nd Avenue, Houghton
Telephone : 011 483 1068
Fax : 011 728 3104
Email : hcpl@54.co.za

Taking part in this research is entirely voluntary. Nobody will be paid for taking part. You may refuse to take part and your decision will be respected. The care you receive at Hospice Soweto will not in any way be different if you do not take part in the project. All patients receive the best care possible.

This form is also available in Zulu and South Sotho.

R E S E A R C H INTO SYMPTOMS RELATED TO AIDS

Information Sheet

Z U L U

Indawo Yokufunda Ngezifo Ezingalapheki
Isasizo kabanzi ngengculazi Nangezimpawu zayo.

Yingani Senza Lolucwaningo
Yingoba isibalo sabantu abagula ngengculazi siyanda kakhulu emzansi Afrika.

Ingculazi isifo esitholwayo uma amasosha omzimba angasakwazi ukuzivikela, leligcwane lenziwa iHIV.

IHIV imele igciwane elibulala amasohsa alwa namagciwane emzimbeni yethu. HIV yenza ukuthi amasosha akhathale angakwazi ukulwa namagciwane. Amasosha aya ngokukhathala njalo, njalo kuze kube isiguli sigula kakhulu.

Leligciwane lengculazi lenza ukuthi uhlushwe kakhulu izinhlungu nezimpawu ezahlukahlukene. Kuye kwaba nocwaningo olukhulu ukuzama ukothola ikhambi lokwelapha ingeulazi noma kunjalo uma ikhambi lingatholakala abantu bazobe begula.

Lolucwaningo lubhekene nezimpawu zabantu aba phila nalegciwane.

Iyini Inhloso Ngocwaningo
Inhloso ye Hospice ukwanzi kabanzi ngezimpawu ezejwayelekile kue kubantu abasebenengeulazi. Lokhu kusiholela endleleni engcono ukuze sikwazi ukuthi umguli akhululeke angagqilazeki ezinhlungwini.

Sizocela Ukuthi Wenzeni
Ukuthi usiphendule imibuzo esizoyibuza
Umhlengikazi uzogcwalisa izimpendulo zakho.
Wena akukho okuzofuneka ukubhale.

Yini Engenza Ukuthi Ungazizwa Kahle Noma Engakufaka Engozini

Lemibuzo iphakathi kwakho neHospice akekho omunye ozokwazi. Asibhali igama nenombolo yekhadi. Sizocela imizuzu embalwa.

Ubani Ozosizakala Kulolucwaningo (Imibuzo)
Sithemba ukuthi odokotela nabahlengikazi (Nurses)
Bazosizakala ukuthola nokwelapha izifo eziphathelene nezimpawu zengculazi, ngokusebenzisisa ulwazi olutholakala kulemibuzo neziguli eziphethwe isifo sengculazi zizosizakala ngalolulwazi olutholakala kulemibuzo.

Ubani ozokwazi ngemiphumela yalolucwaningo (Imibuzo). Imiphumela. Yalolucwaningo izosiwa lapho okugcinwa khona eminye imiphumela yocwaningo ukwenzela ukuthi abanye abantu bezofunda ngayo.

Ulwazi Ngingaluthola Kubani
Udokotela u D A Norval
Hospice Centre for Palliative Learning
Hospice Witwatersrand
50 2nd Avenue, Houghton
Telephone : 011 483 1068
Fax : 011 728 3104
Email : hcpl@54.co.za

Ukuphendula lemibuzo akekho umuntu ophoqwayo ukwenza ngokuthanda kwakho, akukho nemali ozokhokhelwa yona ngokuphendula imibuzo unganqaba uma ungathandi sizohlonipha isinqumo (ilungelo) lakho.

Lolulwazi lutholakala ngesiZulu nangesiSuthu (Sotho).

R E S E A R C H INTO SYMPTOMS RELATED TO AIDS

Information Sheet

SOUTH SOTHO

Lefapha-la Thuto la Mafu A sa Foleng

Lefapheng la Hospice Witwatersrand

TSEBISO

Patlisiso ka Matshwao a Fumanwang Bathong Ba Tshwerweng Ke Kwatsi Ya Bosolla Thlapi

Ke Hobaneng Re Etsa Patlisiso Ee?
Lenaneho la batho ba tshwerweng ke kwatsi ya bosolla thlapi le nyoloha ka potlako Afrika
Borwa.

'AIDS' e emetse lefu le fumanwang ha masole a lekantshang dikokwana hloko a fokola, le etswa ke kokwana hloko e bitswang HIV> HIV e emetse kokwana hloko e bolayang masole a lekantshang dipeo tsa mafu mmeleng ya rona.

HIV e etsa hore masole ana a fokole, a seke a tseba ho lekantsha dipeo tsa mafu. Mokudi o fokola fwalo ho fihlele a kula haholo.

AIDS ha e u tshwere e ya u kodisa ka matshwao a fapaneng.

Dipatlisiso di entswe ka bongata ho leka ho fumana pheko ya kokwana hloko ya kwatsi ya mo solla thlapi, ha hole jwalo ho fihlela pheko e fumanwa, batho ba tla mne ba kule.

Patlisiso ena e shebane le matshwao a fapaneng ao motho ya tshwerweng ke AIDS a bang le ona.

Re Tla Fihlela Eng Ka Patlisiso Ee?
Hospice e batla matshwao a atileng bathong ba tshwerweng ke kokwana hloko ya AIDS. Hona ho tla etsa hore Hospice e fumane mokgwa o tshepahalang wa ho fedisa matshwao, le hore mokudi a kgotsofale a seke a kula haholo.

Re Tla Kopa Hore U Etse Eng
Seo re se kopang ke hore o arabe dipotso tse lokiseditsweng patlisiso ena. Mooki ke yena ya tla tlatsa dikarabo tsa hau, uena ha u no ngola letho.

Ke Eng Tse Ka Etsang Hore Re Se Ikutlwe
Hantle Kapa Ho Na Le Tse Ka Bang Kotsi Na?
Dipotso tse lokiseditsweng patlisiso ha le hlahise lebitso la motho, lebitso la hau kapa karete ya bophelo ba hau ya Hospice ha e na ho hlaha.

Re tla hloka feela metsotso e mashome a mararo a nako ya hau.

Ke Mang Ya Tla Thola Mosola Patlisisong Ena
Re tshepa horepatlisiso ena etla thusa baoki ba Hospice hore ba be le hona ho thusa bakudi ba bontshang matshwao a AIDS.

Le hore sephetho seo tla se fumana se tla thusa dingaka le baoki ho phekola matshwao a fapaneng bathong ba tshwerweng ke AIDS. Le batho ba tshwerweng ke AIDS. ba tla thuswa ke patlisiso ena.

Ke Mang Ya Tla Tseba Sepheto Sa Patlisiso ee?
Sephetho sa patlisiso se tla iswa moo ho bolokwang dipatlisiso tse entsweng hore batho ba bale ka sona, feela hopola lebitso la hau, le dipampri tsa bophelo ba hau ha di na ho hlahiswa ka ha ke lekunutu.

Nka Bua Le Mang Ha Ke Batla Kutlwisiso E Batsi
Dr. D. A. Norval
Hospice Centre for Palliative Learning
50 Second Avenue, Houghton
Tel : 011 483 1068
Fax : 011 - 728 3104
Email : hcpl@54.co.za

Ha ho motho ya tlamellwang ho kena patlisisong ena. Ha ho tefo etla ntshiwa ha u dumetse ho botswa dipotso.
Ha u sa batle, u ka hana, mme maikutlo a hau a tla hlomphuwa.

Tsebiso ena e fumanwa ka leleme la se Zulu le Sekhowa.

ANNEXURE D :

World Health Organisation Staging System for HIV Infection and Disease

Clinical Stage 1

1. Acute retroviral infection
2. Asymptomatic
3. Persistent generalised lymphadenopathy (enlargement of the lymph nodes)

Performance scale 1: asymptomatic, normal activity

Clinical Stage 2

4. Weight loss, <10% of body weight
5. Minor mucocutaneous manifestations (seborrhoeic dermatitis, prurigo (chronic itchy skin), fungal nail infections, recurrent oral ulcerations, angular cheilitis (inflammation of the corners of the mouth)
6. Herpes zoster (shingles), within the last 5 years
7. Recurrent upper respiratory tract infections (i.e. bacterial sinusitis)

And/or performance scale 2: symptomatic, normal activity

Clinical Stage 3

8. Weight loss, >10% of body weight
9. Unexplained chronic diarrhoea, >1 month
10. Unexplained prolonged fever (intermittent or constant), >1 month
11. Oral candidiasis (thrush)
12. Vulvo-vaginal candidiasis, chronic (>1 month) or poorly responsive to therapy
13. Oral hairy leukoplakia (thickening of the dorsal surface of the tongue)
14. Pulmonary tuberculosis, within the past year
15. Severe bacterial infections (e.g. pneumonia)

And / or performance scale 3: bedridden <50% of the day during the last month

Clinical Stage 4 (AIDS-defining conditions)

16. HIV wasting syndrome, as defined
17. *Pneumocystis carinii* pneumonia
18. Toxoplasmosis of the brain
19. Cryptosporidiosis with diarrhoea, >1 month
20. Cryptosporidiosis, extrapulmonary
21. Cytomegalovirus (disease of an organ other than liver, spleen or lymph nodes)
22. Herpes simplex virus infection, mucocutaneous >1 month, or visceral (any duration)
23. Progressive multifocal leuko-encephalopathy (selective destruction of the central nervous system)
24. Any disseminated endemic mycosis (i.e. histoplasmosis, coccidioidomycosis)
25. Candidiasis of the oesophagus, trachea, bronchi or lungs
26. Atypical mycobacteriosis, disseminated
27. Non-typhoid salmonella septicaemia
28. Extrapulmonary tuberculosis
29. Lymphoma
30. Kaposi's sacroma
31. HIV encephalopathy, as defined

And / or performance scale 4: bedridden >50% of the day during the last month