



## Symptoms and sites of pain experienced by AIDS patients

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**Introduction.** HIV/AIDS is the top single cause of mortality burden in South Africa and patients with AIDS present with unique and challenging symptoms and pain syndromes.

**Objective.** To identify and increase awareness of the 10 most prevalent symptoms and 5 most common sites of pain in patients with advanced AIDS.

**Design and subjects.** A nurse-led questionnaire was used to collect data, and a descriptive, quantitative analysis was done. Subjects included 103 adult patients with World Health Organisation (WHO) stage 4 AIDS. Patients with impaired cognitive function were excluded.

**Outcome measures.** The main outcome measures included a list of 30 symptoms, 13 site-specific pains, age, gender, worst overall symptom and access to antiretroviral therapy (ART). Results were based on review of data collected between May 2002 and February 2003.

**Results.** Results showed the mean age of patients to be 35.4 years, with females an average of 4.4 years younger than males. There were a higher number of female respondents

(62.6%) than males (37.4%). The 10 most common symptoms in order of prevalence were pain (98%), weight loss (81%), loss of appetite (70.9%), 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%).

Of the respondents 34.4% mentioned pain as the worst overall symptom. The average number of pains experienced was 2.91. Females reported significantly more anxiety, genital sores and pain than males. Of the patients 3.9% 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.** Patients with advanced AIDS in South Africa suffer significantly from pain and many distressing symptoms. In the light of the HIV/AIDS pandemic in South Africa reforms are needed to increase knowledge and education in the palliative management of AIDS.

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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 still do not have access to anti-retroviral therapy (ART).

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 majority of patients with AIDS currently 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, a day care centre and a 10-bed inpatient unit. The vast majority (80%) of patients seen at Soweto Hospice have AIDS. This study aims to increase awareness of the 10 most prevalent presenting symptoms and the 5 most prevalent sites of pain among AIDS patients in an

urban South African setting. This will assist in the development of protocols for the effective palliative management of these symptoms.

At present HIV/AIDS-related literature in South Africa focuses largely on the potential use of antiretroviral drugs, prevention of mother-to-child transmission, governmental policies and attitudes, epidemiology, vaccine trials and factors in this region causing such rapid spread of the virus. Textbooks and literature also focus on AIDS-related syndromes and tumours.

Very little emphasis is placed on the palliation of AIDS-related symptoms such as pain, cough, dyspnoea, diarrhoea, anorexia, nausea, pruritus or malaise. Further, health care professionals are frequently guilty of shedding responsibility for the care of the patient with the attitude of 'nothing more can be done'.

Even though current ART is 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.

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.

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## Subjects and methods

A descriptive study using quantitative analysis was undertaken. The quantitative approach produced numerical and factual data, from which a statistical and numerical analysis of advanced AIDS was done.

The study sample was drawn from adult patients registered with the Soweto Hospice Programme between May 2002 and February 2003. Subjects selected were AIDS patients over the age of 18 years registered with the Hospice Association of the Witwatersrand (World Health Organisation (WHO) clinical stage 4), with a confirmed positive HIV test.

Patients were excluded if they had a reduced level of consciousness or HIV-related dementia resulting in a Glasgow coma score less than 12 or if their HIV status was undisclosed or unconfirmed.

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.

The setting was Soweto Hospice, primarily an AIDS hospice situated in the urban area of Mofolo, Soweto, a large suburb of Johannesburg.

Prospective analysis was done on initial referral to the in-patient unit or home care programme.

A two-page structured questionnaire was used to collect data in nurse-led interviews with patients. The interviewers were 5 professional palliative care nurses working in the Soweto in-patient unit and home care programme.

All questionnaires were read to patients to minimise patient burden. The questionnaires were translated from English into Zulu and South Sotho, the three most frequently used and understood languages in Soweto. The questionnaires were used to collect data on patient age, gender, and 26 symptoms specific to the central nervous, gastro-intestinal, dermatological and respiratory systems. Constitutional symptoms such as fatigue and fever were also recorded. Thirteen 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).

Lastly, respondents were asked whether or not they had ever had access to ART.

## Results

Male patients comprised approximately 37.4% of the sample, and female patients the remaining 62.6%. The average age of male patients was 38.3 years, and that of female patients 33.9 years (Fig. 1). The average age of observed AIDS patients was 35.4 years. The standard deviation (SD) in the age of AIDS

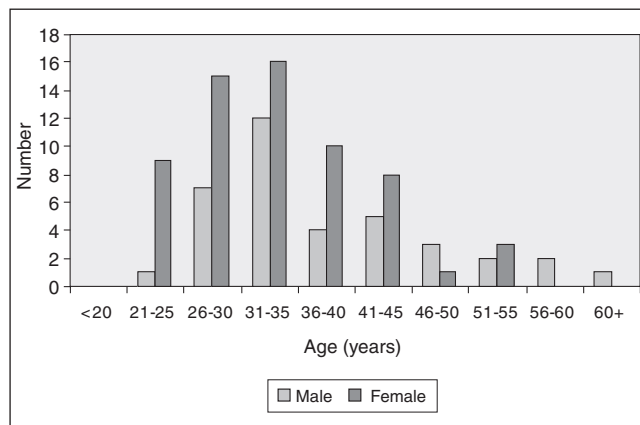


Fig. 1. Age distribution of AIDS patients.

patients in this study was 8.8 years.

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

### Access to antiretroviral therapy (ART)

There were 14 (13.6%) non-respondents to the question of whether or not each patient had access to antiretroviral medication. Four patients (3.9%) had access to ART. Eighty-five patients (82.5%) had not had access to ART (Fig. 2).

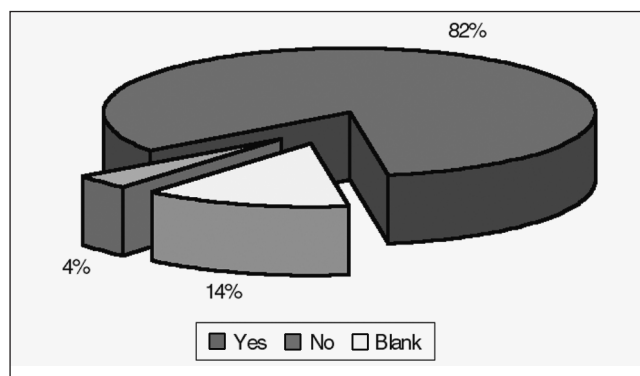


Fig. 2. Access to ART.

Only 3.9% of all patients and 4.5% of respondents (4 of the 89 who replied) had had access to ART.

### Overall 10 most prevalent symptoms (including pain)

Table I shows the symptoms that occurred, in order of prevalence.

**Table I. Symptoms in order of prevalence**

Symptom	Total number of patients	Percentage
1. Pain	101	98
2. Weight loss	81	78.6
3. Loss of appetite	73	70.9
4. Low mood	72	69.9
5. Weakness	68	66
6. Dry skin	58	56.3
7. Diarrhoea	56	53.4
8. Nausea and vomiting	46	44.7
9. Cough	46	44.7
10. Fatigue	44	42.7

## Pain

Pain was the most prevalent symptom (98%), with 34.38% of patients reporting pain as their worst overall symptom.

## Analysis of pain sites

Table II gives an analysis of the sites where pain was experienced.

**Table II. Analysis of the sites of pain experienced by both male and female patients**

	Total	Percentage	Male	Female	Sum
Head	44	42.7	16	25	41
Mouth	52	50.5	16	32	48
Throat	41	39.8	14	24	38
Chest	18	17.5	3	15	18
Abdomen	13	12.6	5	8	13
Genitals	13	12.6	6	6	12
Upper limbs	8	7.8	2	6	8
Lower limbs	68	66.02	24	40	64
Skin	3	2.9	1	2	3
Muscles	15	14.6	5	10	15
Rectum	4	3.9	1	3	4
Backache	12	11.6	3	9	12
Generalised	12	11.6	8	4	12

The most common source of pain was lower limb pain (66%), followed by mouth (50.5%), head (42.7%) and throat (39.8%) pain.

The top 5 sites of pain in order of prevalence were lower limb, mouth, head, throat, and chest (Table II).

**Table III. Genital sores, genital pain, depression and anxiety**

	Male (N)	Percentage	Female (N)	Percentage
Anxiety	6	16.2	15	24.2
Hopelessness	11	29.7	20	32.3
Genital sores	6	16.2	19	30.6
Genital pain	4	10.8	9	14.5

Females experienced significantly more 'anxiety' and genital complications than males. There does not appear to be a significant difference between males and females with regard to 'hopelessness' (often a symptom of depression) (Table III).

## Discussion

Sub-Saharan Africa has the highest incidence of HIV/AIDS in the world and health care workers are faced with an overwhelming number of patients with advanced AIDS. South Africa has the worst and fastest-growing HIV/AIDS epidemic in the world.<sup>1</sup>

In South Africa, AIDS is the leading cause of death. Half of all infected adults are infected before 25 years of age. The percentage of adults (aged 15 - 49 years) living with HIV/AIDS is 20.1%.<sup>1</sup> In this study sample of mainly young black Sowedans, only 3.9% had ever had access to ART.

It is currently estimated that only approximately 30 000 of South Africa's 4.7 million HIV-positive individuals receive ART.<sup>2</sup>

In South Africa, young people are considered a particularly vulnerable group. The mean age of respondents in the study was 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 programme was 38.6 years.<sup>3</sup>

Westernisation and modernisation of African culture has resulted in a lack of clearly defined roles and values for adolescents to emulate. At the same time, because of the economic crisis and poverty, adolescents have been affected in spheres such as education and the meeting of basic needs.

The relatively young age of most people 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.

In 2002 the Nelson Mandela/HSRC study of HIV/AIDS<sup>4</sup> showed that sexual experience among youth was significantly higher in urban informal areas than in other types of localities. The median age of sexual debut among sexually active 15 - 24-year-olds was found to be 16 years.

In reality, young people with AIDS have little support and high stress levels, leading to high levels of depression and mood disorders. This is demonstrated in the present study by the high prevalence of symptoms such as anxiety and hopelessness.

Findings of this research support the fact that women are becoming infected at a younger age, and that there are significantly more women living with HIV/AIDS in South Africa than men.

Reasons why more women are dying of AIDS and at a



younger age, are manifold. A significant body of well-researched and documented social science studies<sup>5,6</sup> give reasons such as early first sexual encounter, premarital and extramarital sexual relations, resistance to requests for condom usage, transactional sex, economic disempowerment of women and biological vulnerability.

There is a great deal of sorrow, anxiety and stress among female patients. This may relate to women knowing that they will not see their children grow up, concern about the HIV status of their children, and decisions about guardianship. In this study female respondents experienced significantly more anxiety than males. It can only be speculated that the above-mentioned reasons contributed to this.

Women with HIV/AIDS often have a very different clinical course from men. Gynaecological manifestations of HIV are common in women. It is therefore essential, when providing palliative care, to be sensitive to the often painful and complicated issues relating to women in the contemporary South African context.

A study by Fontaine *et al.*<sup>7</sup> found that physician recognition of symptoms experienced by HIV patients was low. Symptoms such as diarrhoea, nausea and vomiting that could be alleviated by specific treatment were not recognised and therefore attention was not paid to these potentially treatable conditions.

In this study the mean number of symptoms experienced was 9. Symptom control should not be neglected or reserved for patients in severe end-stage disease; it should be part of the management of all patients at all stages of HIV/AIDS. In advanced HIV/AIDS the most prevalent symptom is pain.

Most doctors in South Africa have received little or no formal training in HIV/AIDS care or palliative care. Suddenly there are too many patients, the specialist clinics cannot cope and primary care level is faced with dealing with this epidemic without clear guidelines. This has resulted in suboptimal and haphazard care. The biggest barrier to care is the anxiety doctors feel when dealing with something they have not been trained in, against a background of overwhelming workloads.<sup>8</sup>

Pain is a common and often neglected or poorly managed symptom of AIDS. People with HIV often have multiple pains occurring concurrently and the pain has a profound effect on their quality of life. Of the 103 respondents, 98% experienced pain and 34% mentioned pain as the worst overall symptom.

A study by Glare<sup>9</sup> on patients with AIDS showed that on average, patients experienced pain at 3 different sites concurrently, with 33% of patients experiencing pain at 4 or more sites. The present study shows a similar trend, with pain occurring on average at 2.9 different sites at one time. 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 severity rating. Pain control is needed, using the WHO analgesic ladder, viz. non-opioids, opioids and adjuvant analgesics as well as non-pharmacological therapy.

There are many challenges to managing AIDS-related pain, including polypharmacy, heightened sensitivity to drug side-effects, psychological co-morbidity, drug interactions and issues relating to the AIDS dementia complex.

Estimates of the extent of under-treatment of pain in AIDS vary but have exceeded 80% among AIDS patients.<sup>10</sup> There is a lack of literature on the incidence of pain and AIDS-related symptoms.

Barriers to pain management in South Africa include lack of knowledge on 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.<sup>9</sup>

Both male and female respondents identified 'lower limbs' as the major source of pain. This pain is most likely the result of a peripheral sensory neuropathy related to HIV. A similar study<sup>11,12</sup> on patients with AIDS before the ART era confirms that lower limb pain is the most common pain experienced. Neuropathic pain 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 is known to be an important site of pain in patients with AIDS. In this study 'mouth' and 'throat' pain were reported in the 5 most prevalent sites of pain. The most frequent causes include oral candidiasis, aphthous ulceration, herpes simplex virus, gingival and periodontal disease, salivary gland disease and Kaposi's sarcoma. There are many different ways to manage HIV-related oral pain palliatively using topical and systemic therapy.

Oesophageal ulceration, tumours and infection often result in severe burning retrosternal chest pain and odynophagia. In a study by Frich and Borgbjerg,<sup>13</sup> upper gastro-intestinal infections were found to be the main source of patient pain, which was of a burning, scorching nature.

Chest pain accounted for 17% of pains in the present study population. A large proportion of South African AIDS patients have pulmonary tuberculosis (TB). Other possible causes of chest pain in the study population include other respiratory infections, varicella zoster (shingles) and post-herpetic neuralgia, TB pericarditis and tumours such as Kaposi's sarcoma and non-Hodgkin's lymphoma.





Headaches are very prevalent among patients with advanced AIDS. Forty-three per cent of the respondents reported the 'head' as a site of pain. There are many documented causes of headache in patients with AIDS, from intracranial infections and tumours to adverse effects of antiretrovirals, sinusitis, migraine, systemic infection and tension headaches.

It is interesting to note that female respondents experienced a statistically significantly greater amount of genital pain than males. Females also reported statistically significantly more genital sores (31%) than males (16%). These findings reflect the fact that in South Africa, women are more vulnerable to HIV/AIDS partly due to an epidemic of sexually transmitted infections (STIs).

### Limitations of the study

The sample included 103 respondents. The sample was sufficient within the scope of this study, but because of the small size, generalisability was limited. The sample was biased in that participation was voluntary and only patients willing and alert enough to take part were included. The study did not, therefore, elicit symptoms from patients who were too ill, confused, or demented.

This study did not assess severity of pain or symptoms, and future studies will need to address these measurements.

In spite of its shortcomings this study is one of the first to examine the pain and symptoms of patients with advanced AIDS in urban South Africa.

### Recommendations

There is very little research on end-of-life issues in HIV/AIDS in South Africa. 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 antiretroviral 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. Even in countries where ART is available, the need for palliative care has increased. In countries using ART the more chronic nature of the HIV disease course results in an increasing burden of cumulative HIV-related morbidity, treatment-related toxic effects, uncertainties about prognosis, increased need for advance care

planning and problems related to limitations of rapidly evolving therapies. Thus even in the ART era the false dichotomy of curative versus palliative care needs to be supplanted by a more integrated model of care.<sup>14</sup>

The science of palliative care, which focuses mainly on the patient and not exclusively on the disease, should be built. More study is needed to explore issues around genital pain and anxiety, which are statistically prevalent among Sowetan women. Specifics of this disease in female patients, and the many issues that arise, need to be investigated more fully.

This research suggests several areas in which palliative care 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.

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

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.<sup>15</sup>

It is hoped that the results of this study will be used to improve palliative care education on HIV/AIDS by identifying common causes of distress, and the significance of pain in AIDS. It is essential that training opportunities in palliative care parallel the growth in palliative care services.

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