



## The role of a palliative care inpatient unit in disease management of cancer and HIV patients

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**Objectives.** To monitor the success of an inpatient palliative care unit combining private and state patients, and accessible to patients with cancer and AIDS.

**Design.** An observational study was conducted of patients admitted to the unit in the first 3 months following opening of the ward (1 March - 31 May 2006).

**Methods.** Data were collected on all patients admitted to the ward to establish patient profiles, duration of stay and outcome of palliative care.

**Results.** In the first 3 months 51 patients were admitted. Of these patients, 36 (70%) (1 readmission) had AIDS. All the AIDS patients had stage 4 disease and all but 3 were on antiretroviral (ARV) treatment. The death rate in the initial 3 months was 38% in the cancer group and 33% in the AIDS group. By the end of the 5th month the death rate was 37.5% in the cancer group, and 27% in the AIDS group. The remainder of the patients were discharged.

The average duration of stay in the ward was 8.3 days. Among those who died, the average stay was 3.8 days for cancer patients and 8.3 days for AIDS patients. Among the

patients who were discharged, the average duration of stay was 7 days for cancer patients and 8.5 days for AIDS patients.

**Conclusions.** The profile of terminally ill patients with cancer and AIDS was initially similar in terms of death rate. In the first 3 months 38% of cancer patients and 33% of AIDS patients died. In the following 2 months the death rate was 33% for cancer patients and 19% for AIDS patients. While the numbers of patients are small and only an indication of trend, the AIDS death rate seems to be dropping. This may be because ARV treatment is being introduced earlier, or because the role of palliative care in the treatment of AIDS patients is gaining recognition and introduction of this form of treatment is having a beneficial effect on outcome. In this hospital it is now accepted that AIDS patients developing symptoms on treatment will benefit from admission to a palliative care ward. This intervention may well improve the outcome in stage 4 AIDS. The duration of stay in the ward is longer for AIDS patients, and it appears that AIDS patients who survive will need a longer stay in the palliative care unit than cancer patients if outcome is to improve.

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Palliative care has traditionally been seen as appropriate in the management of terminally ill cancer patients. With the advent of the AIDS pandemic a new role for palliative care has emerged in the management of AIDS patients who are terminally ill. Palliative care has a role to play in care of patients who are dying, but it may also have a significant role to play in symptom control in terminally ill patients on treatment. Symptom control may improve the response to treatment. In this way palliative care may improve the outcome of treatment<sup>1</sup> and result in patients moving from a terminally ill to a chronically ill state.

Terminally ill patients have problems related to symptom control, emotional distress and psychosocial concerns. Typically the spin-off effects relate not only to the patients but also to the families and carers, both family caregivers and non-family members who have been employed to help with care giving. Inpatient palliative care units have a role to play in helping to develop treatment plans for symptom control, in assisting with the burdens of care at the end of life, and in providing respite care for the family and caregivers. Family caregivers

are placed under an enormous strain and easing of that burden is an important part of palliative care.<sup>2</sup> Caregivers typically have unmet needs for information, communication, service provision and support from health and community services.<sup>3</sup>

Relieving the burden experienced by carers allows the home situation to continue for longer and with less stress and breakdown. Without a backup system, carers may reach a point where they are unable to continue care of the patient at home.<sup>4</sup> This breakdown results in patients being dumped on the overburdened state health services. The role of palliative care units in providing respite care to relieve the emotional, physical and psychological stresses of carers is well recognised.

However it has been recognised that access to palliative care is influenced by social class and age in the Western world.<sup>5</sup> Kessler *et al.*<sup>5</sup> showed that patients from social class 5 were less likely to die in a hospice, largely because of passivity in seeking support and information. Conversely, it has been shown that hospital-based advanced home care enables patients to die at home if they so wish.<sup>6</sup> Catt and co-workers<sup>7</sup> showed that older people were also less likely to receive palliative care.

Apart from socio-economic factors, access may also be influenced by preconceived ideas about the disease profiles associated with the need for palliative care. In particular in the South African context where the AIDS pandemic continues unabated, the role of palliative care in AIDS management

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is increasingly being recognised, and with the changing life expectancy profile of AIDS patients, the dichotomy between curative and palliative care has now become inappropriate.<sup>8</sup>

## Background

Grahamstown is a small town in the Eastern Cape, served by a district hospital catering for a population of 180 000. It is conservatively estimated that 36 000 people are HIV-positive, and as the pandemic continues more and more are starting to reach the terminal phases. The hospital statistics show that on average 30 people a month have been dying of AIDS (0.01% of the infected population per year). The local hospital was selected as a rollout site for ARVs in 2004, and with an enormous amount of effort nearly 680 people have been receiving this treatment. As the programme began it became evident that by the time patients started to receive medication they were in stage 4 of the disease, with multiple medical problems, and some of them were terminally ill.

At the same time the need for palliative care for cancer patients was growing, given the ageing population of retirees in the town. Cancer patients have to travel to Port Elizabeth (120 km away) to the oncology units at the private hospital or the state hospital. After receiving chemotherapy they have to drive back to Grahamstown, using either private transport or the rather erratic ambulance service. Once back in Grahamstown palliative care was undertaken by hospice using home-based care. There was no inpatient unit. At the point where home-based care became insufficient, patients would be admitted to a general ward in the local hospital where they would occupy a bed in the crowded ward until they died. Alternatively they were sent back to Port Elizabeth to the oncology units. Relatives would only be able to visit them in the local hospital during visiting hours, and if they were in Port Elizabeth, only over weekends.

These two populations tended to be diverse in that the one population was elderly and affluent, and the other was much younger and often unemployed, with no financial means.

To address the problems of both groups in the community, the concept of a public-private partnership in the development of a palliative care unit was explored. With the help of a service organisation (Rotary), First National Bank and Hospice as the private partners, and the Department of Health as the public partner, an agreement was reached to provide a palliative care ward. The private partners refurbished an old unused ward in the hospital and the state provided the staff. The role of Hospice was to support the patients in hospital and then take over the management on discharge.

## Methods and patient profile

The planning process was undertaken between the state and Hospice, and the private partners were involved in decision making in the refurbishment process.

Addressing the needs of these two groups led to the concept of a palliative care unit that would accommodate the needs of all the patients. This required a unit with individual wards that would allow for privacy for the patients and also enough space for relatives to stay during the day and even overnight if they wished. The environment needed to be peaceful and there needed to be space for a lounge and a quiet room.

An unused building at the back of the hospital, previously used for geriatric patients, was identified as a place for the new unit.

The unused unit had 3 large wards. One of these was converted into 6 single-bed units. Three 4-bed wards and an office were converted into larger single-bed units. This gave a total of 10 individual wards, 4 larger units for private paying patients and 6 smaller wards for state patients. Each ward has a basin and a comfortable chair for visitors. Extra beds are available for visitors to stay overnight. In addition the unit has a lounge with a TV and a quiet room. The remaining large wards have been designated for training purposes and a step-down facility. There is a boardroom and offices for the nurses and social workers.

Admission criteria were planned carefully. Patients had to have fulfilled the criteria for being a hospice patient, and a primary carer had to be identified at home who would be available to assume care of the patient on discharge. This was to avoid the problem of patients being dumped in the unit.

Staff in the ward underwent palliative care training by attending a course or by doing ongoing in-service training covering the following topics: admission criteria; the dying patient's bill of rights; the role of symptom management; the use of the syringe driver for administering medication; hospice patient information and file; hospice mission, vision and philosophy; orientation to patient assessment and holistic care; what constitutes palliative care; the role of staff in this ward; psychosocial orientation; history of hospice care; and the interdisciplinary team.

The ward was opened in March 2006. A daily ward round was done by the sisters in the ward and the palliative care doctor. A weekly ward round was done by the palliative care team, the clinic members involved with ARV rollout, the social worker, dietician and hospice team.

The patient profile for the study period shows that the majority of the private patients (10% of the total patient numbers) had cancer, and all but 1 of the AIDS patients were state patients.

Relatives of the private patients stayed with them during the final days of the illness. Relatives of the state patients visited frequently but were less likely to stay with patients unless they were out of town, in which case they only stayed over weekends.



Local patients were visited by carers, family members or non-professional carers hired by the family; on these visits it was possible to train carers regarding home management.

Treatment in the palliative care ward focused on alleviation of symptoms, and patient needs. It involved the use of morphine for pain and diarrhoea and in small doses for dyspnoea, haloperidol for nausea and confusion, non-steroidal anti-inflammatory drugs (NSAIDs) for bone pain, lorazepam for anxiety, and other medications commonly used in the palliative care setting. In the case of patients with opportunistic infections, palliative care included use of specific medications as well as palliative care medications. Fungal infections were common and were treated with topical fungicides, oral fluconazole and topical glycerine and local anaesthetics. Similarly, diarrhoea was common and was treated with Bactrim, dapsone, oral morphine, Imodium or appropriate antibiotics. In patients with severe vomiting or uncontrolled pain, oral morphine was not always effective and morphine was then given using a syringe driver, which is a small mechanical battery-driven machine that pumps morphine subcutaneously via a butterfly needle, allowing a very small dose to be given constantly over a 24-hour period. Palliative care included the use of intravenous fluid in some patients, mouth care, nutritional support and food supplements and symptom-specific treatment of other problems. All discharged patients were visited at home by one of the Hospice sisters, and sometimes the social worker. All AIDS patients were on ARVs or initiated on treatment by the ARV rollout team. Modifications to the treatment were initiated by this team as needed.

The majority of discharged patients were sent home because they had improved. Very occasionally, relatives decided to take a patient home to die. Generally, by the time patients were admitted for terminal care it was because the relatives had been unable to cope and were very distressed. All discharged patients were followed up by the hospice sisters, who were able to report on conditions at home. Follow-up by the sisters included report back on when patients died, which was sometimes weeks to months later. All AIDS patients were followed up by the ARV team. Although a formal assessment of patient condition on follow-up was not undertaken, informally the outcome was an improvement in the situation at home in at least 80% of cases.

Interaction between the ward staff, social workers and the hospice home-based carer has proved to be valuable in the resolution of difficulties at home. This was exemplified by the situation with a 23-year-old male patient who was repeatedly readmitted with diarrhoea. It was established that the water source at his home was heavily polluted with environmental organisms and that this was the source of his ongoing diarrhoea.

## Results

Fifty-one patients were admitted in the first 3 months (Table I). Of these, 36 patients had AIDS and 15 had cancer. About 30% were admitted from the HIV clinic and the medical ward and the remainder were from hospice. All the patients were eventually taken over by hospice, working in conjunction with the clinic. The outcome in 16 cases was death (6 of these patients had cancer) and the rest were discharged. Among those who died, the average duration of stay in the ward was 3.8 days for cancer patients and 8.3 days for AIDS patients. Among the patients who lived, the average stay was 7 days for cancer patients and 8.5 for AIDS patients. The AIDS patients tended to stay longer because of the complexity of their problems on presentation. Almost all of them were already on ARV treatment but not doing well, either because of side-effects, late initiation of treatment with very low CD4 counts, or immune reconstitution syndrome (IRIS) reactions. Without admission to the ward they would probably have died.

During the first 3 months the death rate among cancer patients was 38%, and in the following 2 months the death rate was 33%, with an overall death rate of 37%, but the numbers were small and the change is of doubtful significance. By contrast the death rate among AIDS patients was 33% in the first 3 months and 19% in the second 2 months, with an overall death rate of 27%. Again the numbers are probably too small to be anything but an indication of a trend, but they do suggest that good palliative care management influences outcome in these very ill patients.

## Discussion

It has increasingly been realised that successful AIDS treatment requires a combination of disease-specific and palliative care therapies<sup>9</sup> as the disease becomes a more chronic condition resulting for some patients in a protracted course of symptomatic illness. However, it has been recognised that HIV specialists may have a restricted concept of palliative care, considering that it should only be used in terminally ill patients and only after all curative treatments have failed.<sup>10</sup> This view is often combined with a reluctance to use morphine analgesia.

However, Butters *et al.*<sup>11</sup> have shown that symptom control, anxiety and pain have been significantly improved in HIV/AIDS patients receiving palliative care. In the African context where poverty and poor home conditions militate against symptom control, attention to the palliative care aspects may well improve the overall outcome of treatment. All centres involved with the rollout of ARV drugs should also apply the principles of palliative care medicine to management of these patients.



**Table I. Patient profile (age and gender), HIV-related diagnosis or cancer type, and outcome in patients admitted to the palliative care unit, Settlers Hospital, Grahamstown, 1 March - 31 May 2006**

Age (yrs)	Sex	AIDS	Cancer	Outcome
59	F	TB gastroenteritis		Discharged
41	F	Diabetic		Discharged
44	F		Cancer of the mouth	Discharged
60	F		Cancer of pancreas	Died
54	F	Confusion		Transferred
33	M	Hepatitis		Died
55	F		Cancer of lung	Discharged
62	F		Cancer of oesophagus	Died
35	M	Gastroenteritis		Discharged
35	F	Confusion		Discharged
59	F		Cancer of oesophagus	Discharged
42	M	PTB/MDR		Died
71	F	Diabetes		Died
81	F		Cancer of cervix	Died
34	F	Gastroenteritis		Discharged
43	F		Cancer of lung	Discharged
59	F		Cancer of cervix	Discharged
44	F		Cancer of mouth	Discharged, died at home
23	M	PTB/gastroenteritis		Discharged
25	F	TB		Discharged
48	M	Pneumonia		Died
66	F		Cancer of liver	Died
23	M	PTB/gastroenteritis		Discharged
43	M	Cryptococcal meningitis		Died
31	M	Kaposi's sarcoma		In ward 31 May
23	M	TB/gastroenteritis		Readmitted
26	F	Weakness/loss of weight		Discharged
41	F	Diabetes		Died
38	F		Breast cancer	Discharged
37	F	PTB		Discharged
30	F	Abscess		Discharged
59	F		Cancer of lung	Discharged
31	F	Tonsillitis		Discharged
47	M	TB, candidiasis		Discharged
83	F		Cancer of liver	Died
26	M	PTB		Discharged
44	F		Cancer of cervix	Discharged
42	M	AIDS		Died
56	F	AIDS		Discharged
31	M	Kaposi's sarcoma		Discharged
23	M	Diarrhoea and vomiting		Discharged
28	F	Septicaemia		Discharged
37	F	PTB/septic wound		Discharged
36	F	Gastroenteritis		In ward
23	M	Gastroenteritis		Discharged
42	F	AIDS		Died
60	M		Cancer of oesophagus	In ward 31 May
23	M	Gastroenteritis		Discharged
59	M	PTB		Discharged
23	M	Oesophageal candidiasis		Died
42	M	Vomiting		In ward 31 May
40	F	Weakness		Discharged

TB = tuberculosis; PTB = pulmonary tuberculosis; MDR = multidrug-resistant.

## Conclusion

This study demonstrated that implementation of palliative care principles reduced the death rate of HIV patients admitted to a palliative care ward.

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