

# PLIGHT OF AIDS PATIENTS IN RURAL SOUTH AFRICA — A CHALLENGE TO HEALTH PROFESSIONALS

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*'There is nothing we can do for you! Why did you come now!'*

*'There are no medicines to give you! Go home! come back tomorrow.  
There is no doctor today! Why don't you look after your child!'*

All of the above are a sad reflection of many of our rural health facilities. Nurses who are already demotivated, inadequately trained for the huge responsibilities they have to carry, and frustrated by the lack of resources, now have to carry the extra burden of seeing people dying daily of AIDS in their communities, often friends and family members. Frequently, out of a sense of inadequacy and hopelessness, they respond in anger and frustration. The patients in turn, lose hope in the formal government health system, and turn instead to any other source where they can grasp for hope for a cure.

Many go to the 'special doctor', the general practitioner, who is also overwhelmed by patients to whom a cure can no longer be offered. Because patients want to get their money's worth, GPs are often pressured into prescribing inappropriate medication or resorting to alternative medicine, reassuring patients that they will get better with this 'special' treatment.

Many others turn back to their traditional healers, where they attempt to get some spiritual explanation for their sickness, perform some rituals, and receive some traditional medicine, which they are assured will cure them.

Finally, having spent all their money, and in debt to neighbours and friends, the family attempts to care for the dying relative at home. News may get around that there is AIDS in the house, neighbours and friends cease to visit, the children are ostracised at school and drop out, and there is no income, apart from possibly the granny's pension, and little or no food in the house. In desperation they attempt to go to the clinic to ask for a disability grant, often sitting in queues for many hours, and are usually told they don't qualify. If they are successful, many months will pass before the grant is processed, by which stage the extra

funeral costs have added to the huge debt of the family and/or orphans.

This is the situation I, as a rural doctor in Mpumalanga, find myself facing on a daily basis. The challenge that faces me, like many other rural doctors, is how to improve the plight of the thousands of PWAs in our rural areas of South Africa.

Talking to Department of Health (DOH) professionals and managers, the problem is a lack of finances to provide basic medication, transport and staff at the clinics. Talking to the patients and their families, their biggest need is food and painkillers. Digging a little deeper, there is a need to be treated with respect and dignity, and to be accepted by the health system.

In my search to see how other African countries have coped with the AIDS epidemic, I visited Uganda, where I stayed at the Mildmay AIDS Hospice in Kampala. I also visited Hospice Uganda, and several community home-based care projects. I observed the patients, rich and poor, streaming into Mildmay Hospice. I was surprised that there were no inpatient beds either there or at Hospice Uganda. The patients were greeted with a big smile and, 'You are welcome. We are so glad you came today. I can see you are suffering. How can we help you?'

I asked if I could sit in at the paediatric HIV clinic, and the doctor stood up and shook my hand and welcomed me to his clinic. He introduced his patient, aged 8 years, and asked permission for the doctor from South Africa to be present during the consultation. The little patient replied, 'You are very welcome.'

I could hardly hold back my tears as I saw again the very

basics of medical care – treating patients with unconditional love, warmth, and respect. Treating them as precious human beings in the sight of God and their fellow human beings.

Most of the terminally ill patients in Uganda are cared for in their homes, by community home-based care volunteers. These volunteers receive excellent training at places like Mildmay and Hospice Uganda as well as other centres.

A multidisciplinary team from Mildmay goes out into the communities every Wednesday to run workshops for the family members caring for terminally ill patients at home. At the workshop I attended, which was held at a church hall, the physiotherapist demonstrated how to lift and turn patients. The nutritionist spoke on how to prepare nutritious meals for the patients. The nurse spoke on how to manage persistent diarrhoea at home, and the counsellor spoke on how to manage a difficult patient. There was a lot of participation from the group. Finally, the pastor encouraged and prayed for the family members, and then cooldrinks and cakes were provided.

Mildmay provides an HIV outpatient clinic, which operates on a Monday, Tuesday, Thursday and Friday. Patients are assessed firstly by a professional nurse, and then by a doctor. They are then referred as necessary, to the appropriate member or members of the multidisciplinary team. The team consists of an occupational therapist, a counsellor, a nutritionist, and a pastor or spiritual counsellor. Basic laboratory tests were done while the patient was visiting various members of the team. Finally, patients would collect their medication from the

pharmacist, and pay according to their means.

A good supply of medication was available, including morphine suspension, oral antifungals and antivirals, as well as prophylactic treatment. Those who could afford it, and had had extensive counselling, were offered antiretrovirals. They also had more extensive laboratory tests including CD4 counts and viral loads. There was an excellent follow-up and monitoring system.

I came home with hope in my heart again, and a vision of what we could do in South Africa. From small beginnings we have a home-based care programme operating in the Northern Nzikazi area of Mpumalanga. Sixty wonderful community volunteers visit the chronically and terminally ill patients in their homes, and provide holistic care, including basic counselling, nursing care, directly observed therapy, practical help and social and spiritual care. In the year 2000, 17 000 visits were recorded and at present 500 patients and 600 orphans are being cared for in their homes. Modelled on Mildmay, we are building a clinic and training centre to provide support to the home-based care projects. We also endeavour to provide palliative care training to the nurses and doctors at the government clinics and district hospital.

I believe that this is a model that can be replicated in other rural areas. I also believe that there are many health professionals who are willing and wanting to provide compassionate quality care for AIDS patients, whether rich or poor. I believe this is what we as South Africans need to strive for, and not settle for anything less.

