

**Treatment and Support:**  
***Is it possible to provide quality care and support to HIV/AIDS patients  
in rural South Africa?***

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**Introduction**

Today when I see the hundreds of people living with AIDS (PWAs) pouring into the ACTS clinic every month, I think back to five years ago when it was just a dream. As a South African doctor who has worked in the rural areas of South Africa for the past 30 years, I had seen many diseases associated with poverty, but never such suffering and death, especially in young people.

Ten years ago when, as a government community doctor, I started working in the Masoyi Tribal area, I began to see patients with the signs and symptoms of HIV/AIDS. I wanted to see how the countries to the north of us were handling the epidemic, and heard of a project in Zimbabwe, Family AIDS Caring Trust (FACT), and so my husband and I spent two weeks on a training course with them.

We came back to South Africa, met with the local chief and tribal authorities, and received permission to call a mass meeting of the community and local churches to present the problem of HIV, and see if the church women were interested in receiving training in home-based care. There was great interest and 20 women from 10 different local churches came forward for training. At that stage we had no funding and no curriculum, but they were trained in very basic nursing care, home care, and record keeping. They were each given a notebook, and told to go out in twos to find anyone who was very ill. That was the beginning of the Masoyi Home-based Care (HBC) project. This project has grown in size and now has a very successful orphan care program.

However, I soon realized that HBC without professional medical care and treatment could not work. I hoped that patients could be referred to the local government clinics for this, but there was a lack of basic medicines and skills in the clinics, as well as the fact that the patients felt stigmatized, and didn't want to go to the clinics. They were often told, "Go home, there is nothing that we can do for you." This was a reflection of many of our rural health facilities. Nurses who were already demotivated, inadequately trained for the huge responsibilities they had to carry, and frustrated by the lack of resources, now had to assume the extra burden of seeing people dying of AIDS in their communities, often friends and family members. Frequently, out of a sense of inadequacy and hopelessness, they would respond in anger and frustration. Many of the patients would turn back to their traditional healers, where they attempted to get some spiritual

explanation for their sickness, perform certain rituals, and receive traditional medicine, which they were assured would cure them. Finally, having spent all their money, and in debt to family and friends, the family would attempt to care for the dying patient at home, or reject them.

Once again in my search on how to improve the plight of the thousands of PWAs in the rural areas of South Africa, I turned to the north. I heard of success stories coming from Uganda, and was fortunate enough to be sponsored to fly to Uganda, where I visited the TASO project (The AIDS Support Organisation), the Mildmay AIDS Hospice, and other church projects. I observed the patients, rich and poor, streaming in for care. The patients were greeted with a big smile and the words, "You are welcome." I asked if I could sit in at a pediatric AIDS clinic, and the doctor stood up, shook my hand and welcomed me to his clinic. He introduced me to his patient, aged eight years, and asked his permission for the doctor from SA to be present during the consultation. The little patient replied, "You are welcome." I could hardly hold back my tears as I saw again the very basis 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. I came home with hope in my heart again, and a vision of what we could do in South Africa.

I also firmly believe that a continuum of quality care and support for HIV/AIDS patients and their families *can* be provided at a primary care level at relatively low cost.

### **Case Study: AIDS Care Training and Support (ACTS)**

Modelled on what I had seen in Uganda, we opened the ACTS clinic in May 2001 in rural Mpumalanga. We are so grateful to GlaxoSmithKline (GSK) for taking a chance with us, and entering into a community partnership program. GSK United Kingdom sponsored the start-up costs of building and equipping the extensive project we now operate. They provided funds for the first three years. Our mission statement was to provide a continuum of quality care and support for all those affected and infected by HIV/AIDS and to model this in the Masoyi Tribal area. The Masoyi tribal area has a population of 250,000, poor infrastructure, poverty, unemployment and a high incidence of HIV, infecting 38 per cent of the sexually active population.

Due to the stigma attached to the disease we initially wondered if anyone would come to the clinic. At that stage we had no access to antiretroviral drugs (ARVs), so all we could offer was treatment of opportunistic infections and palliative care. Word spread through the community that patients were well treated, and people began to pour in, desperate for any kind of help. We felt that we were offering the best in pain and symptom control and the treatment of opportunistic infections but still I was signing two death certificates a day. I knew that ARVs were available, but they were far too expensive to obtain and the patients could never afford them. The handful of patients that were on ARVs did remarkably well and I was desperate to get ARVs for all our patients. Ten thousand patients had passed through our doors, and approximately a thousand patients would have benefited from ARVs at that time.

In 2004 the price of ARVs dropped significantly, and so did the laboratory tests that were needed to monitor the disease and the treatment. There was a rise in assistance from first world countries to support Africa in its fight against HIV/AIDS, and funding began to be available for treatment. In November 2003 I was signing an average of two death certificates a day; today I am signing two death certificates every month.

ARVs alone, however, are not the answer for Africa or any other country, but if they are used correctly in a comprehensive program they can have a huge impact on the mortality rate among young people, the number of orphans and the poverty in Africa.

## **Essential components of quality care and support**

### ***Voluntary Counselling and Testing***

Voluntary Counselling and Testing (VCT) is the entry point for quality care and support. Whole families and communities need to know their HIV status. This is of vital importance in both prevention and treatment. At ACTS we offer VCT to anyone who comes to the clinic. The doctor or nurse may offer VCT to patients showing signs and symptoms of HIV (medical referral), or patients may request VCT (self-referral). Since the advent of ARVs the number of self-referrals has risen sharply. The sense of “what is the use of knowing my status, as there is nothing that can be done,” has changed to “I must know my status, and get treatment.”

Pre- and post-test counselling is done by lay counsellors, who are local community women, trained by ACTS. The doctor or nurse does the rapid finger prick tests. Patients are praised for coming forward to have the test. We find that clients with a negative test are highly motivated to stay negative, and those with positive tests are given hope, and encouraged to join a support group, and a treatment plan is initiated.

### ***Support Groups***

Once patients know that they are HIV positive, they need a support group. At the beginning it is often difficult for them to share their result with their sexual partner, family and friends, although they are strongly encouraged to do so. In the support group the issues of disclosure are discussed, as well as positive living, nutrition, safe sex, ARVs, breastfeeding, and many others. At present we have 16 support groups. Each consists of 10 to 20 members, and they meet on a monthly basis. Each caters to a different group of people. We have support groups for HIV-positive mothers and children, young women, older women, young men, older men, couples and teenagers. On their support group day, the patients see their doctor or nurse for a medical check-up and receive their medication, including ARVs if prescribed. They then go to see their counsellor, who does a pill count, and reinforces adherence, and listens for any other problems. The patients then join their support group, where they share problems and encourage each other. The support groups have become very popular, and patients often stay most of the day, chatting in groups under the trees, with the children playing in the

playground that has been set up. Volunteers from various churches often provide tea and refreshments, as well as training in handcrafts. They also like to have times of prayer and singing.

One of the most moving times for me was when the support groups organized a surprise party for the two doctors at ACTS. They collected a little money and chose gifts which they presented to us, along with singing, dancing and speeches from all the groups, to convey their gratitude for the care that they had received. One granny shared that she could sleep again, as she didn't have to get up all night to clean up the diarrhea, and wash the clothes of her daughter. Another said that she thought that she would never live to see her baby grow up, and others said they were dead, and now were alive again.

### ***Medical assessment***

Medical assessment is vital to the program. The initial assessment is usually done by one of the two doctors working at the clinic. This may be done prior to, or following, VCT. The patient is staged according to the World Health Organization (WHO) HIV clinical staging: Stages 1 to 4. Opportunistic infections, especially tuberculosis, are actively looked for. Pain and symptom assessment is also given high priority. The doctors rely on basic clinical skills of history taking and physical examination, as no sophisticated diagnostic equipment is available. There are always comments from visiting medical students or doctors who rediscover their clinical skills. Follow-up medical assessments are done by nurses trained in primary health care. Ideally, nurses trained in HIV assessment and management should be able to see the majority of patients, with a doctor acting as a consultant for up to 10 nurses.

### ***Treatment***

At ACTS we use the basic drugs on the essential drug list (EDL) for primary health care. We have developed protocols for the management of common opportunistic infections, for example: chronic diarrhea, oro-pharyngeal candidiasis, sexually transmitted diseases, herpes zoster and herpes genitalis, pneumonia, skin rashes, and tuberculosis. At times we have to refer patients to the district hospital for the investigation and management of more difficult problems such as meningitis, suspected toxoplasmosis, and severe anemia.

We use cotrimoxazole for the prophylactic treatment for PCP pneumonia, and toxoplasmosis. We also use a wide range of vitamins and immune boosters.

We follow the palliative care guidelines for the management of pain and other symptoms. Oral morphine solution, codeine, amitryptoline, and haloperidol are all very useful and relatively inexpensive drugs for palliative care in a rural setting.

### ***Antiretrovirals (ARVs)***

The price of ARVs has fallen dramatically in the last year, and ARVs are now affordable in Africa. We are very grateful to the pharmaceutical companies for their commitment to the poorer nations.

We are also very grateful to USAID through the NGO, "Right to Care," for funding for our ARV program.

We have three criteria for initiating ARVs at ACTS:

1. WHO staging, usually Stage 3 and 4
2. CD4 count below 200, unless stage 4, or children
3. Readiness for ARVs:
  - The patient must have accepted their HIV status;
  - They must have disclosed to at least one family member;
  - They must be part of a support group and attended for at least three months;
  - They must have received at least three sessions on adherence counselling.

We always use triple therapy, and follow the South African Department of Health Guidelines for first and second line treatment. First line is usually D4T, 3TC and either Efavirenz or Niverapine.

At present we have 250 patients on treatment, only two patients on second line treatment, and a 98 per cent adherence rate.

ARVs have had a huge impact on our care for HIV/AIDS patients. I could tell hundreds of stories of patients who were either carried into the clinic on a blanket, or in a wheelchair, who are now fit and well, caring for their children, instead of their children caring for them, and once more able to work. One young woman, Fikile, describes how she was lying in a government hospital bed, with patients dying all around her, when she heard about ACTS, and she begged her friends to hire a car and bring her here. I remember the day she arrived. She looked like a skeleton, she was not able to swallow, and too weak to stand up. We admitted her to our little community hospice, treated the esophageal candidiasis, gave her sips of oral rehydration salts (ORS) to drink, and then soft porridge. We treated her other infections, and slowly she grew stronger. She had a CD4 count of 4, which is extremely low, but we decided to give her a chance on ARVs. Within three months she had gained 20 kilograms and bubbled with energy and excitement. Every time she came to the clinic she would bring friends and neighbours, as sick as she had been, and she would visit the other patients in the hospice and encourage them by telling them that she had been worse than they were.

Another patient that will always stay in my memory is little Siabonga. His mother had died and his granny looked after him. He was three years old, but always sick. He had chronic diarrhea, fevers and was too weak to even sit up. At one stage we admitted him to our hospice, and I felt that he would not be alive in the morning. But he was, so we decided to tube feed him, treat all the infections and see what happened. Once again he responded so well that we called in the granny, and asked her whether she would be able to give him ARVs, if we explained it all carefully to her. Siabonga and his granny visit us every month, the granny smiles from ear to ear, and Siabonga is now running around and playing with all the other children. On his last visit he came to show his HBC

nurse his new shoes. Unfortunately she had left to work in England, but when I phoned to tell her, she just cried, as she had built up such affection for Siabonga, and his Gogo (granny).

### ***Laboratory monitoring***

Laboratory tests are expensive, and always a problem in rural areas. We have been fortunate in receiving funding for the transport of specimens and for basic, essential laboratory tests. Once again the cost of lab tests has come down. We do a CD4 count, which measures the strength of the immune system; ALT which is a liver enzyme, and monitors toxicity to the liver; and FBC which measures the red and white blood cells, at baseline. We repeat the CD4, FBC and ALT at three months, and do viral load, CD4, ALT, and FBC at six months and every six months thereafter, unless otherwise indicated. The viral load should be undetectable at six months. This is an indicator that signifies excellent compliance. Sputum specimens are also sent for microscopy if TB is suspected, and if negative the patient is referred for chest X-ray. Pap smears are taken if early cancer of the cervix is suspected.

Basic laboratory tests are essential for any patient with HIV, especially if they are on ARVs. Tuberculosis, which is so common in HIV patients, is curable. Cancer of the cervix, which is also very common in young women who are HIV-positive, is preventable if detected early. Relatively inexpensive laboratory monitoring can also prevent toxicity from ARVs.

### ***Home-based care***

Home-based care (HBC) has become a buzzword in AIDS care in Africa. This is because the hospitals did not have enough beds for AIDS patients. There was also a general feeling that there was nothing that could be done for AIDS patients so it would be better for them to go home to be cared for by family and community caregivers until they died.

I believe that home-based care still has an essential place in Africa, but that it must be part of a comprehensive program, otherwise it will result in HBC neglect.

At ACTS we have a nurse trained in primary health care who visits bed-bound AIDS patients in their homes. She receives referrals from the Masoyi HBC community volunteers. She does the initial medical assessment in the home, and then leaves a care plan for the volunteer to follow, or transports the patient to the clinic or the community hospice.

There needs to be training, monitoring, evaluation and support for community caregivers, if they are to provide quality care and support to patients in their homes. A good model developed by the Hospice Association is that of 10 community caregivers supported by a registered nurse. Each caregiver cares for approximately 20 patients. The caregivers can also support the patients in their TB and ARV treatment. They have a

large part to play in orphan care and skills training as well as HIV awareness and prevention.

One of the greatest challenges for the HBC team is providing care in conditions of extreme poverty. Cultural beliefs often make it difficult to provide treatment. Many patients believe that they have been bewitched, or that a curse has been placed upon them. They may be rejected by the family, or terribly afraid to be known as HIV positive. Elsie is a typical example of a patient who was referred to our HBC team. She was found lying on the floor of an outhouse, covered in feces. She was dehydrated, as she was unable to get up to fetch water from the stream. She had been rejected by the family. The HBC team were able to improve her condition enormously by cleaning her up, providing water at her side, and sending in a caregiver to see that she had fresh water and food on a daily basis. They also provided oral rehydration salts (ORS) to replace the salts lost from the diarrhea.

### ***Community Hospice***

We have established a very basic six-bed hospice in the community. There are three criteria for admission to the hospice:

1. Pain and symptom control
2. Terminal care, when it is not possible at home
3. Respite care for the relatives.

The length of stay should not exceed five days.

A retired nurse, together with community caregivers runs the hospice. A doctor from ACTS does a brief ward round daily. The patients receive excellent nursing care, as well as spiritual support. The unit is very cost-effective, and well received by the community.

Solomon, a dear old gentleman, begged me not to send him to hospital. He was extremely ill with what we call reconstitution syndrome. We had just started him on TB medication for TB glands in the neck, and because his CD4 count was only two, I had decided to also start him on ARVs. However this caused a severe flare-up of his glands, and he could hardly breathe. I persuaded him to be admitted to the hospice, which was right in his community. He agreed, and later was so happy because his family could walk to visit him and he received loving care from a retired nurse from his community.

### ***Training***

Training is essential for every member of the team—doctors, nurses, counsellors, community caregivers, administrative and management staff. ACTS has received accreditation from the Health and Welfare Sector Training and Accreditation Authority, and from the Hospice Palliative Care Association of Southern Africa as a training site.

## Conclusion

I firmly believe that it is possible to provide quality care and support to people living with HIV in Africa at a primary health care level at relatively low cost.

What is needed to provide that care?

- A clear vision and leadership
- Community involvement
- Skilled and committed healthcare professionals
- Funding for running costs, and capital expenditure
- Medicines and equipment
- Training, monitoring and evaluation programs
- Excellent project, financial and human resource management.
- Help from Above.

I am grateful to my wonderful staff at ACTS for their dedication and loving commitment to the thousands of patients who pass through the clinic, hospice and HBC. Many of the PWAs themselves keep us in touch with the beliefs and expectations of the community.

“You are welcome”—a phrase brought back from Uganda—has become part of ACTS. Patients, no matter how sick or dirty, are treated with dignity and respect by every member of the team.

This project has been empowered and supported by wonderful sponsors, ranging from the big pharmaceutical GSK and USAID to the faithful gifts from churches and individuals. Not only money has been provided, but also equipment ranging from medical equipment to bricks and supplies, from toothpaste to curtains and bed linen. Many others have come as volunteers and freely shared their skills with us. Our huge thank you to the many that have supported ACTS.

Our motto at ACTS is from the Bible: “I have come that they may have life, and have it to the full” (John 10:10). And so we give grateful thanks to our Heavenly Father who we believe cares far more than we can understand for each one of his creations.

*Dr. Margie Hardman is the founder and director of the ACTS Community Clinic—a clinic with a special focus on HIV/AIDS/TB and cancer patients among the poor in the Peebles Valley near White River in South Africa.*