AIDS: The continuum of care in Ingwavuma

"This is not a time for indecision and prevarication. It is not a time for preoccupation with supposedly insuperable difficulties. Nor is it a time for indefinite plan-making. It is - especially - not a time for grandiose schemes designed to attain perfection. It is unlikely that in our lifetimes we will attain perfection in Africa. Let us attain something less than perfection in the lives of enough Africans to save them from death by AIDS."

Justice Edwin Cameron, New York, 2001

Few people deny that the AIDS epidemic is now with us. Out of 973 clients tested by the Mosvold Hospital AIDS Team in 2002, 74% were HIV positive. There are now queues outside the mortuary every Friday of relatives coming to collect bodies for burial at the weekends. The debate is "What is the function of a doctor in all of this?" Should we continue working purely as clinicians fighting opportunistic infections and providing palliative care to the growing number of incurable patients or do we need to rethink our role in the light of this epidemic which is devastating the population and changing the whole make-up of society?

I have been working in Northern KwaZulu Natal for over 5 years and have seen my job shift from clinical medicine to a public health focus. While working in the hospital I became frustrated by the lack of services available to support clients outside the hospital. Terminally ill clients had the choice of staying in hospital with some nursing support but far from their relatives or dying at home with their families but with no medical support. Much illness was exacerbated by poverty, poor nutrition and non-existent sanitation. At one stage we had 4 orphans living in the hospital grounds because no one knew what to do with them while other vulnerable children would be admitted with malnutrition only to be sent back to starve again once they had improved.

The funding available from government coffers was not easily available and did not cover all the services which we felt were necessary in order to provide a continuum of care to families affected by the epidemic. Therefore set about fundraising for projects to care for orphans, enhance life skills teaching in the schools and provide a home based care service. Funding for the orphan project became available late in 1999, while funding for the school project and home based care came late in 2001.

Home based care

"Home Based Care" can mean different things to different people. In our case we have 20 carers supervised by a nurse. The carers are all people chosen from the communities they serve who have received one month’s training at South Coast Hospice followed by a month’s practical experience working in Mosvold Hospital. They work in teams or individually in their immediate neighbourhoods and get around by foot and bicycle. The nurse is employed by the hospital and her job is dedicated to home based care. She visits each team of carers every one or two weeks providing them with encouragement, ongoing training and supervision. She visits difficult cases with the carers and supplies basic analgesics and other drugs.

The carers have excelled themselves, going beyond providing direct care or training to family members. Many are active as HIV counsellors and have
encouraged families to come forward for testing together, then provided them with ongoing support. Others spend weekends teaching in churches and community meetings. Clients are either referred by the community health workers or by the hospital. In the first year of operation this project cared for 436 patients who had 5423 visits between them. Each visit cost the project R40 in addition to the costs incurred by the hospital for the nurse’s salary, drugs and nursing supplies.

As the carers see that a client is deteriorating, they refer the family to the orphan care project. The carers report that it is a relief to hand over the children to another organisation rather than worry about what will become of them once the parent has died. The orphan worker helps the family to prepare all their identity documents so that once the parent has died they can quickly enter into the foster care grant system. When this works well, it can take as little as 2 months from the death of the parent to the processing of the grant. In the meantime, the children may receive assistance with food parcels and clothes.

**Orphan project**
The orphan project employs 3 co-ordinators, one for each tribal authority in the health sub-district. These staff all have tertiary education and travel around by bakkie. While some of the work involves dealing directly with families, the staff is also active in community mobilisation, in educating people about their rights and in advocating for these rights. With 850 families and around 2000 vulnerable children, it is impossible for them to provide direct care to all the families so empowering grass roots community groups to do this work is vital. The co-ordinators have different specialist skills to offer including counselling and psychological support, agricultural expertise and training in starting up businesses. Our aim is to ensure the children are cared for, get an education and are able to sustain themselves as they grow up.

**Schools project**
The schools project is currently active in 10 of the 80 schools in the health sub-district. One staff member provides support to the staff and pupils in finding ways to make the AIDS epidemic seem relevant to them and planning how to fight it. At Christmas a group of 50 learners from the 5 high schools went on a camp where they discussed issues around AIDS in depth. These learners are now forming action groups and acting as peer educators. While many teachers have been trained to teach life skills, the schools appreciate assistance from outside as the teacher-pupil relationship does not always allow children to open up and discuss intimate topics such as sexual relationships and self esteem. As well as addressing personal risks for HIV, the learners discuss their feelings towards people who are infected, AIDS orphans and other vulnerable people. Thus the project helps break down stigma and discrimination in the community, enhancing the work of the home based care and orphan projects.

Managing these projects is a far cry from seeing patients in the outpatient department. Yet I feel that it is still fulfilling my role as a health care provider in that it meets many of the objectives of primary health as defined at Alma Ata.

There are currently no posts for “AIDS Doctors” in the government service. But given the magnitude of the epidemic and the complexity of its impact on society I would motivate that such posts be created. There is far more to fighting the epidemic than treating those infected and providing broad prevention messages.

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