

Reflections and lessons from frontline treatment providers

Providing access to antiretroviral treatment in Southern Africa is very different from doing the same thing in North America or Europe. In the following article, **Belinda Beresford** reports on the progress of several treatment programmes in urban settings in South Africa and Botswana. Based on interviews with doctors and patients, she provides a number of important insights on the challenges that lie ahead.

Things fall apart, the centre cannot hold (W. B. Yeats)

The rapid evolution of AIDS-related medicine has led to centres of treatment excellence which are usually located around specialist, tertiary hospitals. This trend is accompanied in Southern Africa by the general shortage of skilled medical personnel – the brain drain of doctors and nurses to western countries is well-documented. People who stay tend to be in the better equipped facilities, which are usually in the larger population centres. As a result, existing antiretroviral treatment centres tend to be located around capacity, rather than need.

Yet antiretroviral therapy is a long-term chronic care programme given to patients who, when established on the treatment, are generally healthy and productive. But ambulatory care, especially when compliance is such a fundamental requirement for success from both a personal and a public health point of view, is not appropriately given at specialist hospitals. It would be preferable to provide such care in a primary health care setting, bringing the treatment to the patients rather than the other way around. The physical distance patients have to travel simply to collect their medicine risks creating a creeping patient inertia, and finally non-compliance. The health and economic costs of this are well-documented.

From rural areas, such as the Lusikisiki programme in a remote part of South Africa, to hospitals in major cities such as Johannesburg and Gaborone, different ARV sites show the flaws and difficulties of running treatment programmes that are based on traditional medical demarcations and structures, rather than those more appropriate to the environment and the human and physical infrastructure.

Coronation Hospital, Johannesburg, South Africa

Coronation Hospital in Johannesburg provides an AIDS clinic for children under the guidance of Dr Ashraf Coovadia. Part of the government's national treatment plan, the clinic has been assigned a dedicated clerk and healthcare workers. The paediatric clinic is part of a spectrum of HIV-related care available at the hospital, cobbled together from a range of funding sources. Patients at the clinic range from birth to 15 years of age. After that they go to the Helen Joseph Hospital close by, although at the moment, Dr Coovadia says, most HIV-positive children are dead long before that age.

The waiting period for a Thursday morning clinic is now one month. Roughly thirty patients are booked in at a time, but more usually turn up. The problem for children, with their developing bodies, is that delay may not cost them their lives, but it could affect their physical, mental and emotional growth. Children are more prone to central nervous system damage as a result of HIV/AIDS, leading to developmental slowdown and even irreparable physical or intellectual damage. Initially the clinic prioritised the sickest first but it now operates on a first-come, first-served basis. The change was brought about by sheer numbers of sick children, so that prioritising almost became irrelevant.

Providing ARVs for children is more complex and time-consuming than for adults. In itself, 'children' is a very large category. So a doctor or nurse at a paediatric clinic needs to have equal confidence and knowledge about treating a six-week-old baby, as a 14-year-old teenager. Young children's immune systems are underdeveloped, and they may react differently than adults, both in response to the disease, and to the drugs. As a result, many doctors hesitate to treat children because of the complexities involved.

There are simple practical problems: children need to be reassured about being seen by the doctor, and often may still feel that they want nothing to do with it. So while in an adult taking a blood sample can involve just a couple of minutes, in a child the health worker may have to spend time reassuring and explaining – and then still ending up with three adults having to hold down the thrashing body of the uncooperative patient.

Adherence and treatment counselling for children needs to be tailored to the age of the child – and to the understanding of the caregiver. All too often this is the grandmother, who may find it difficult to understand the disease, or its treatment.

Not least of the problems facing paediatricians is providing the actual drugs. For all classes of medicine, there are more adult than paediatric formulations. In the case of ARVs this means that if a syrup form of a drug is not available, patients have to be given divided and crushed adult pills and tablets. This is not ideal, because it means the actual dosage the child takes is not exact. ARV dosages for children tend to be calculated on the weight, or the surface area of the child, and so change with the growth, or decline, of the patient. For the same reason, standard ratio combined pills, such as Combivir (AZT + 3TC) for adults, are not available. As a result, children can

end up having to take more pills each day than adult patients. It is generally believed that success of treatment is directly related to the pill count – the fewer the number of pills that have to be taken each day, the more likely the patient is to remember them. So the challenges of giving ARV to children are greater for both doctors and patients.

Coronation has a specialist paediatrician hired for the roll-out, and otherwise is assisted by hospital doctors who have spare time. The clinic has two nurse practitioners being trained to treat HIV patients in primary healthcare facilities. But accessing specialists for unusual problems can be difficult: for example, the ENT specialist only works on a part-time basis, and in August is already booked up until February.

Another impediment to the efficiency of the clinic is, paradoxically, a government attempt to facilitate the roll-out: data collection forms. Long and cumbersome, with information that doctors frequently don't know, they are superficially filled in, and much complained about. As Dr Coovadia points out: 'People constructing the forms did not ask clinicians what is needed on the forms. The idea is good, it helps inform clinicians on decision-making and to provide information on the roll-out. The result is bad. Doctors either ignore the forms, or fill in as much as possible, a time-consuming procedure.'

But for the Coronation Clinic, the biggest problem is lack of space. The ARV clinic does not have a permanent home, instead running on a Thursday in a shared polyclinic. The waiting room is too small, and there are only six consulting rooms when at least eight are needed to get through all the patients in the allotted time. As a result, consultations often have to take place in shared space, making it more difficult to gain the patient's confidence, and making confidentiality almost impossible.

Most, if not all, of the children at the clinic were infected with HIV by their mothers during gestation, birth or breastfeeding. Many of them consequently have been orphaned, and are being raised by their grandparents or other family members. This causes psychological problems, which are often not addressed in the pressure to treat physical problems.

One doctor comes to ask about a ten-year-old boy who is wetting his bed at night. The two doctors decide that it is likely to be the result of trauma rather than a physical expression of the illness – the boy started soiling the bed just before his mother died of AIDS. Another young patient doesn't mention his mother at all. He is six weeks into

antiretroviral therapy: He started in the week that he was in hospital, and his mother was dying in another ward. Two psychology students were due to start providing counselling for the children and their families, but doctors admit that all too often the children are slipping through the therapy support net.

Mothers are encouraged to have CD4 tests done, so that they in turn can be cared for properly, and if necessary fast-tracked onto the adult antiretroviral programme. The clinic encourages parents to start disclosing information to the children when they are about six years of age. But many mothers face a horrible dilemma: sharing the burden of a child's HIV status could be cathartic, but since it almost inevitably also discloses the mother as being infected, she risks losing her partner, and often her home..

Children born to HIV-positive mothers are tested for HIV with a PCR test at six weeks. It is more than twice the cost of a standard Elisa test, but the latter cannot be performed reliably until the child is at least 18 months old. 'If you wait for an Elisa, more than half will be dead before the diagnosis. Also, the mothers suffer, wondering are my kids infected,' says Dr Coovadia. He feels that earlier, and more expensive diagnosis, is more cost-effective in the long run. It allows for more effective management of HIV-positive children, who can be treated for illnesses, and given antiretroviral therapy at the correct stage, while they are still healthy. This in turn means a greater likelihood that the child will remain healthy, saving a huge amount in medical and hospitalisation treatment for opportunistic infections.

The ideal scenario is for children to be treated in the same clinic as their parents. Such a family clinic would reduce the amount of money and time spent at the hospital, since parent and child could be seen together. Yet attempts to start such a family clinic have so far been unsuccessful. For Dr Coovadia, the ideal plan would be to link up with the adult ARV clinic at the Helen Joseph Hospital nearby. The problem is one of geography. Both clinics rely on hospital doctors to help them out. If the paediatric clinic moves to Helen Joseph, it is less likely to get extra help from doctors working at Coronation, simply because it will be too time-consuming for them to drive between the two hospitals.

Dr Coovadia's hopes rest on plans to build a prefabricated clinic, with eight consulting rooms, as well as rooms for lectures and counselling. A prefab structure was chosen in an attempt to accelerate the building process. But the Department of Public Works has declared that it must nonetheless go to tender, which the doctors fear means that it will take months or years to build the clinic.

The problems facing the clinic are a result of its success. A growing difficulty is the need to get children to return monthly. As the programme is stepped up, new patients will start becoming crowded out by existing patients returning for follow-up visits or even just collecting their medication. Dr Coovadia points out that there is a critical need for a referral network for children, so that they can be seen at venues closer to home, and less overwhelming, than the hospital.

Johannesburg General Hospital, Johannesburg, South Africa

A similar problem is occurring in central Johannesburg, at the Johannesburg General Hospital (Joburg Gen), which has been struggling to cope with high patient demand from the inhabitants of the city centre. Escalating numbers of HIV-positive people becoming aware of their status, has meant a rising demand for ARVs. 'If even an estimated 30 per cent of the local HIV population is referred to us, the clinic will be overwhelmed', says one of the clinic's doctors, Dr Francois Venter.

The problem was exacerbated by the rational response of people to the lamentable state of primary healthcare clinics: they try to bypass them and head straight for the greater resources at the hospital. As a result, the hospital decided to stop holding its HIV Clinic, and to replace it with a Friday morning antiretroviral clinic. This clinic only accepts patients who either have an AIDS-defining illness, or a CD4 count of less than 200. To obtain antiretrovirals, patients must also show that they have the ability to adhere to counselling and follow-up.

The primary health care facilities are supposed to act as a sieve, diagnosing and caring for HIV-positive people who do not yet need antiretrovirals. Until very recently, confusion at clinic level meant that they did not act as this barrier to hospital entry. Although they had the budget to conduct CD4 and staging tests, many clinics refused to do so. Now that their responsibility for such diagnostics has been made clear by the health department, the primary health care clinics have taken much of the strain from the hospital. Despite this, demand is so much greater than the department of health anticipated, that clinic staff appear to be running twice as fast just to stay in one place. 'Government estimates of patients were based on a lag phase in take-up. But there isn't a lag phase. Or maybe there is. God help us if this is the lag phase', says Dr Venter.

Waiting times to get an appointment are very long, up to five or six months. But with a backlog of very sick patients who needed to be on ARVs several months ago some will die if left to the mercy of the 'first come, first served' appointment-making process. One example was the patient with a CD4 count of 10, who in August 2004 was given an appointment for February 2005.

The bottleneck to treatment was the price of antiretroviral drugs. Now the medicines are available at the Joburg Gen, but treatment is still rationed because of lack of time. Researchers (Rosen; Sanne *et al*) have pointed out that unless rationing is done explicitly, people will do it themselves. Patients will get access to treatment because they know the healthcare workers, because they can pay a bribe, or simply because they don't have a job. The current system discriminates against working people, who may find it harder to get time off work to sit in long queues, or attend repeated adherence counselling sessions. There are attempts to triage, for example fast-track pregnant women, but no formal system.

The biggest problem for Joburg Gen is not enough staff, and in particular they have a shortage of nurses. More nurses are being hired, but in the meantime the clinic just runs for the one day a week. Nurses and counsellors, often the same people, are in a way more important than doctors because they encourage adherence, says Dr Venter. 'We need more days and more staff, we could easily run five days a week. But then we risk ending up with the whole of Gauteng here. It's an emotive issue, but there is a public health limit. It's not the role of the hospital to save Gauteng'.

With such limited clinic time, it will take many months to catch up with the backlog of potential patients. And each day more people qualify for treatment. The problem is also growing because of the system, which requires patients to return once a month to collect the next month's drug supplies. The result is that repeat patients are crowding out the new ones, again slowing down the numbers of people being put on ARV treatment.

Like Dr Coovadia at Coronation, Dr Venter believes that the government will have to change the structure of the national treatment programme, because lack of human resources will make it impossible otherwise to treat all patients who need it. The most obvious solution, he believes, is to send patients who are settled on a regime and doing well to collect their drugs from primary health care clinics on a monthly basis, rather than requiring them to return to the hospital. But that in turn increases the risk of treatment failure, or severe side effects, not being picked up in time, because of the low level of skill and infrastructure at so many public health clinics.

Princess Marina Hospital, Gaborone, Botswana

The same need to decentralise antiretroviral therapy from tertiary hospitals is expressed by Dr Ndwapi, from the Princess Marina Hospital in Gaborone, Botswana. This hospital is almost certainly the biggest single provider of antiretroviral treatment in the world. Two and a half years after its launch, the ARV clinic at Princess Marina Hospital provides antiretrovirals to approximately 8 300 patients. Roughly 15 to 25 new patients a day come through its doors. A normal day sees approximately 250 patients for consultations, and another 200 picking up their medication.

The high profile over the last few years of the government's free ARV treatment plan for everyone has had positive payoffs for the clinic. Patients tend to attend the clinic earlier, and in a better state of health. As a result they are likely to respond better to the drugs, and possibly have less dangerous side effects. Dr Ndwapi says Stigma has decreased and there was a 46 per cent increase in VCT uptake in Botswana last year alone. Almost all of Ndwapi's patients have disclosed their HIV status, and 95 per cent voluntarily bring adherence partners to the clinic. Economic or logistical problems are the main reason the remaining five percent do not bring their treatment supporters. Only a very small percentage of patients don't want to disclose to anyone, and they tend to do worse on treatment.

Dr Ndwapi estimates that the clinic could treat up to 11 000 people. But even that large number would be too small for the capital city of the country with one of the highest prevalence rates in the world – estimated up to 40 per cent. The impact of ARVs has yet to be significantly felt in hospital admissions – it is thought 70 per cent of in-patients at the Princess Marina are there for AIDS-related reasons.

And so the challenge for the medical workers at the Princess Marina hospital is how to maximise their client base and ensure existing patients stick to the treatment regime. Access to drugs is not a problem, and nor is government commitment to the ARV programme. Stigma is decreasing as the sheer number of people infected, and the growing evidence of successful treatment means the disease is becoming more normalised.

Ndwapi estimates that conservatively 85 per cent of patients are adhering to their treatment programme, given that only 8 per cent have been moved onto first or second line treatment. But he is honest about expecting patient dedication to taking the drugs

to decline. Patients who were very sick when they started antiretrovirals know what failing means – many must have been expecting to die. But as patients who are still well enter the programme, they have less experience of the pain and suffering the disease can create, and therefore both the carrot of good health, and the stick of fear of ill health are less effective.

Probably the biggest problem facing the clinic is the final point in the chain – giving the drugs to patients. By lunchtime the waiting room at the clinic is still full, even though most people will have turned up before 7 that morning. The majority of people still sitting are waiting for their drugs. In Botswana a pharmacist has to actually dispense the drugs, but there is a shortage of pharmacists.

Botswana has no medical school, and no pharmacy school. Doctors and pharmacists are trained in other countries, either in the SADC region or sometimes further abroad. Dr Ndwapi, for example, did his medical training in the United States. He says that over 90 per cent of doctors in Botswana are not citizens of that country. It is difficult and expensive to recruit and train healthcare workers, and it can be even harder to retain them.

Dr Ndwapi sees the success of the antiretroviral treatment programme as depending on an evolution of the health system to make it fit the needs and resources of Botswana better. He is critical of some of the traditional divisions between different disciplines, and between doctors and other healthcare workers. 'The biggest challenge facing Princess Marina is how to create a new healthcare delivery system by breaking down barriers between the disciplines, and changing the flow of medical care', he said.

The government planned for 20 000 people to be on antiretroviral therapy in 2002, a figure that was only reached in 2004. The result has been an under-utilisation of planned and budgeted expenditure and resources. 'There's always an impression that it is money that is needed, but that's not true. It's not just resources, the whole system needs to be re-educated in its approach to healthcare. The only solution in the end is primary health care, but because so little was known about the special needs of HIV treatment, and the scale of the problem, it has taken a long time to internalise the need for change.'

Dr Ndwapi feels that this change towards a more primary health care delivery system is going to be the biggest challenge over the next couple of years. 'Manpower is always

an issue. But one of the biggest bottlenecks is the system itself. It is doctor-driven. So every patient must have seen a doctor, and this is not going to allow you to treat the kind of numbers you need. What is unique about these patients is that they are very young people committing to the health care system indefinitely. It cannot work the way things are, you have to liberalise the system, and develop the lower skilled manpower so patients don't have to come to hospital. The system itself is a problem; it's too rigid, too traditional and too conservative. It's the single biggest obstacle outside resources. We now need ARVs to become not a specialist item, but just very basic healthcare. My goal is that I don't want this kind of attention. The ARV programme should fade into the background'.

Conclusion

Going by the experience of existing treatment facilities, mass ARV therapy is not going to be effective without rapid evolution of treatment protocols to meet the demands of clients and the capacity and resources of the health system. While the numbers of patients is still relatively small, the existing healthcare structures are coping, albeit inefficiently. As demand grows the struggle to cope is getting worse – six month waiting lists for dying patients is not a sign of success.

Patients in turn are facing unnecessary handicaps in accessing treatment – taking a day off a month to sit in a queue for medicines is not efficient and sometimes not sustainable. Nor is expecting women with families to look after and food to grow, to walk for two hours to collect their medicines.

The current system is also not equitable. It is resulting in implicit rationing; patients who are geographically closer to a treatment facility, or who can sit in long queues without risking their livelihood, are unfairly at an advantage.

Combating HIV/AIDs requires a hybrid public health response: It has to curb the spread of an infectious disease, and it has to be a chronic care programme, that will almost certainly involve treating patients for the rest of their lives.

To be effective, treatment programmes in Southern Africa have to provide a spectrum of assistance that includes prevention of infection, and minimising illness, and later treatment – and in the worst circumstances – palliative care.

And this all has to incorporate the social elements of HIV/AIDS, including the fact that the disease, unlike most other chronic conditions, especially hits hard among the economically active. The only effective way to attempt to provide such a holistic service is through primary health care facilities. Yet, as the doctors and nurses actually providing treatment know, building the human resource and infrastructure capacity is a grindingly difficult process. But possibly not quite as difficult as creating urgency, creativity and flexibility in the minds of policymakers and administrators.

