

HATiP

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Professional roles and ARV provision

Summary

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It is clear that large-scale treatment for HIV will depend on re-thinking the use of human resources if it is to have public health benefits.

Health care staff working in multi-disciplinary teams providing long-term HIV care may find their roles changing over time in ways that will need careful management.

The role of nurses is of particular importance in many settings, and there is clearly scope for expanding that role with appropriate training and support. Nurse practitioners trained to prescribe a range of medicines and nurse-led clinics are among the options that need to be explored. Specialised pharmacists can also take on a major role in supporting people with HIV on treatment.

A system that chooses first-line regimens that can be managed with limited direct involvement from doctors will be able to make more use of other health care staff in managing them. Human resource issues are therefore directly connected with the development of national treatment guidelines.

Lay involvement, starting with peer support, may also be needed for a successful large-scale treatment programme. A variety of models for peer support and treatment education are available for use.

Social stigma doesn't automatically disappear when services are established (though treatment certainly helps to overcome it). As well as training, resources are needed to prevent occupational exposure to HIV.

Continuing professional support and development are needed by all staff involved in delivering HIV treatment, and not only in relation to ARVs.

The Human resource challenge

With the World Health Organisation and an increasing number of governments setting targets to expand access to antiretrovirals (ARVs), many people are asking not only how the drugs can be paid for but who is going to manage them, and how? And can this be done without losing the capacity to deal with other serious health problems?

The very limited number of doctors in many countries raises the question of how much work can and should be delegated or transferred to other health care staff, or indeed to community workers. In some countries there are concerns over scarcity of nurses and social workers and there is international competition for their services. Yet other countries are believed to have substantial numbers of professionally trained staff who are not working in health services but could return if resources permit.

Several countries have seen the need to increase all health care salaries, to support the inclusion of treatment and care in an enhanced national response to HIV and AIDS. International donors have also had to recognise that staff must be adequately paid, if scarce and expensive drugs are not to be diverted into private

channels to boost their incomes. It may be equally necessary to review non-monetary rewards and recognition too, in order to retain and develop staff with the range of skills and the level of long-term commitment that will be needed.

In Botswana's emerging public health care ARV treatment programme, it has been found that doctors have been treating a sicker population of people with HIV than had been expected before the programme started. As a result, each patient requires more time than allowed for, to evaluate and treat HIV-related diseases. This has slowed the rate at which new patients could be started on treatment. On the other hand, it was found that nurses were spending a lot of their time counselling patients and that lay counsellors were significantly under-used. In order to expand the programme as originally hoped, it has been necessary to work towards better management and definitions of the roles of doctors, nurses and lay counsellors.

In Chiradzulu District, Malawi, Médecins Sans Frontières is extending an ARV programme to primary health care centres, from bases in two district hospitals, with the aid of a travelling clinical team. At first, the travelling doctors held clinics at local health care centres on a weekly basis, moving around the district. However, the plan is to train the staff at the primary health care centres to run their own HIV treatment clinics. The role of the visiting team will then change to one of providing support and advice to local staff, rather than being the direct providers of clinical care.

Also in Malawi, the Lighthouse Clinic has developed a model of care in which doctors hand over responsibility for repeat prescriptions to a nurse after the first six months. A 'smart card' electronic system allows the nurse to give three repeat prescriptions before the patient then needs to be reviewed again by the doctor in charge.

A theme that emerges from much recent discussion is the need for wider access to voluntary counselling and testing (VCT) and for treatment education to begin during the counselling process.

REGENSBERG: In South Africa, we will need to treat a sicker population than expected (as in Botswana). Our experience with Aid for AIDS (AfA) and over 20,000 patients supports this. In general, people come forward late, often because they were simply unaware of their HIV status and it was only discovered after they were hospitalised for a serious AIDS-related illness. In fact, 44% of AfA members joined when their CD4 counts were <200, and 15% when their CD4 counts were <50. It is crucial that as many people as possible undergo VCT so that ARV treatment can be offered before people become ill. This will reduce the healthcare burden substantially.

GREEN: VCT is the key entry point. We're still at the situation where most people are not aware of their infection, and only become aware at a very late stage. Earlier detection might initially add to the load, but with greater availability of ART could save many doctor hours treating OIs. If we can find cases earlier, and get them on to treatment at an appropriate time, we can save huge amounts of health care resources in management of OIs. We can also implement more effective prevention campaigns among those already infected, and thus hopefully reduce the future load.

PRABHU: Expansion of ARV access is important but the means to do so are definitely not in place. The virtually nonexistent and sluggish primary health care system in our country and the poor cooperation between private-public health care sectors are recipes for failure for any system-wide ARV expansion programmes, that may need to be implemented on a large scale quickly. Universal access of all patients to ARV drugs, while welcome, needs to be

implemented only after a clear vision of who to treat - with a clear roadmap of what the next step is going to be.

"We are already struggling with chronic non-infectious diseases, where models exist for dispensation of drugs on a weekly or monthly basis. Problems of access, quality and long term compliance are very much evident even with such common problems as diabetes, hypertension, and epilepsy. Corruption, red tapism, favouritism and "babu raj" are evils which we are struggling to overcome. Add to this, the undermining of the system from within, where public servants also conduct private practice and divert what not, outside...

Multidisciplinary teams

HIV care in most countries and settings depends on multidisciplinary teams, although it can take time to develop these. Even well-established services often lack some professionals such as trained specialist pharmacists who could be invaluable.

It has been argued that the role of the HIV specialist doctor becomes ever more central as the multidisciplinary team expands, as he/she needs to take overall responsibility for the treatment and care provided, even though the individual patient may only rarely be seen by that specialist. Additional and different resources may be needed, for example, to enable doctors to take on a greater role in training colleagues. However, even this role may need to be shared and delegated.

ROUX: All practical tasks and functions regarding ARV delivery can be delegated, providing there is someone experienced at hand with whom to consult. A system of 'mentorship', where more experienced workers are available initially to demonstrate and later to oversee management works well. Another application of this basic idea is to develop capacity and skills through a 'hen and chicken' approach where those who have been trained can train others - while still being assisted through a dendritic support network.

"We have not quite achieved multidisciplinary because our pharmacist is not part of the clinic (yet) and our counsellors are still learning about the specific adherence problems we encounter. We have had access to HAART for 18 months now and have just accumulated enough information on the 150-odd children we have on treatment to have some sort of idea of what is going wrong and why - not much by the way, our figures compare well with those recently quoted out of Africa.

"When it comes to acknowledging people's roles, and non-monetary rewards, the reward of seeing well children running around the clinic goes a long way to providing affirmation. I think an opportunity for each health care worker to write down a job description - followed by a joint review by worker and supervisor would help to chart subtle changes.

"In my view the doctor becomes more of a facilitator, consultant and supervisor - but it's a delicate balance because one also wants to be a hands-on part of the system that delivers continuity of care. The 'hen and chicken' idea, if it includes sufficient time to rotate through a 'base clinic' and satellite clinics, would spread training capacity.

GREEN: All of the major hospitals in Indonesia have long had an 'AIDS Working Group', which is usually multidisciplinary. However, few of these groups have had any real impact partly because only recently have the hospitals started to receive a significant number of AIDS cases. Some of these groups have taken responsibility for management of ART in their area.

"I suspect that the possible degree of delegation is greater than the willingness of the profession to delegate. My experience is that

doctors are very protective of their positions. There clearly is a need to convince the profession that lay people can play a role&

"In Indonesia, we hear stories of nurses and other professionals who are unwilling to move into counselling, primarily because there is no career structure in this 'profession', but also because it is a tremendously stressful job.

REGENSBERG: We support fully the concept of a multidisciplinary team. In our programme, the bulk of the disease management is in fact done by a group of trained pharmacists and nurses supported by two full-time doctors and several part-time HIV Specialists. In practice the doctors/consultants only deal with the more complex cases or where there is multi-drug resistance. The nurses and pharmacists are kept up to date by encouraging them to attend CME meetings and regular training sessions are held.

ORRELL: In our programme in Guguletu, Cape Town, the doctors do only the clinical piece. All the education is handled by therapeutic counsellors. Each patient is assigned a counsellor at the commencement of therapy three patients per counsellor. The counsellors are HIV positive themselves and have had three weeks of training as treatment support personnel. The nurse takes bloods, dispenses drugs and makes appointments.

RABKIN: The MTCT-Plus Initiative [which operates in several African countries] was designed from the start to utilize multidisciplinary teams, based on the success of this care strategy in resource-rich settings as well as recognition of the human resources constraints in resource-poor settings. Our training programmes include whole teams, and emphasizes the need for regular team meetings, interdisciplinary communication, and the involvement of lay providers, including peer educators.

PRABHU: Delivery of these services needs to be through an HIV dedicated team, since it requires a lot of time, commitment and allocation of resources to ensure that workers in the field are adequately paid for, which is very important. Units of these HIV teams could be set up in different regions with training and overall supervision by experts in the field, to ensure that processes run smoothly and that anyone who accesses these services get the best quality of clinical care available. Even if it takes a longer time to implement, quality must not be sacrificed. Involvement of peer educators, nurses and other health workers is welcome, as long as a central HIV physician who understands the issues is at the helm of affairs and steering the boat along.

BENTWICH: Physicians still need to be assessing progression of disease and drug adverse effects. That said, there is growing reliance on physician assistants (when they are available) and of course on nurses. Generally these two categories can take on much of the work load off physicians. Our setting has not suffered from under staffing and so it is difficult to compare to developing countries. However from experience I gained in Africa, the development of multidisciplinary teams is doable and extremely worthwhile. The doctors have to adjust to their new roles of educators of larger staffs and as leaders of multidisciplinary teams, but the most successful and "ideal" model would be the one that succeeds in maintaining some sort of direct role in the treatment of patients aside from the leadership and educational roles. There is no substitute for a good role model. The more responsibility and commitments there is in the leadership the more the staff and people are ready to take such roles themselves.

Nurse practitioners and clinical officers

While medical training for doctors invariably implies a high level of knowledge and skills, the functions for which nurses and clinical

officers are trained, and which they are licensed to carry out, vary from country to country.

In theory, the extent to which nurses and clinical officers are allowed to prescribe medication may set limits to their ability to run services. In practice, many services could not operate without nurses in particular being prepared to take on extra responsibility, and the challenge is to secure training and support to match this need.

In South Africa, for example, the status of ARVs on or off the Essential Drugs List may determine the legal ability of nurses to prescribe them. However, with present drugs and present levels of experience and training in using them, widespread nurse prescription is not being advocated by members of HATIP's advisory panel.

There may also be variation in roles between settings, for example, between nursing in a national or district hospital and in a primary care clinic. It is often the case that in remote districts nurses take on higher levels of responsibility than they might do in an urban setting, simply because, too often, they may simply have to work on their own.

Another major influence on health care staff roles is the extent to which informal care is expected provided by family members, including when a patient is hospitalised.

GREEN: In theory, only doctors can prescribe in Indonesia. In practice, in community health centres in remote areas where there is no doctor, nurses are often allowed to prescribe, although the drugs they can prescribe are effectively limited to the few which are available at the centre or local chemist (commercial pharmacists, most of whom have very little training in Indonesia). In reality, there is no effective policing of the sale of prescription drugs, and most that are available can be easily obtained without a prescription. Morphine is about the only exception.

"Most TB treatment is currently managed by hospitals, or community health centres, for which the note above applies. As far as I know, there is only a very limited number of TB clinics in Indonesia. Mostly these have a doctor, although the doctor may delegate prescribing authority in his absence.

ORRELL: In South Africa, Clinical Nurse Practitioners undergo a year of primary care training and they can then prescribe up to a Schedule 4 drug. They also dispense off a doctor's script for up to 6 months.

"TB treatment generally depends solely on nurses doctors do a clinical review at the beginning of treatment, 2 and 6 months.

REGENSBERG: In South Africa, registered nurses in the public sector with a primary healthcare qualification may prescribe according to our Essential Drug List (EDL) guidelines, which are based on the WHO EDL. This includes repeat prescriptions, and includes treatment of other relevant conditions such as tuberculosis and STDs. This is in accordance with Schedule 38A of the Nursing Act. The latest edition of our EDL is about to be published, but I'm not sure if it includes ARV. If it does, then clearly there is enormous potential to include nurses in a substantial way in any public sector rollout. There are far greater restrictions in the private sector, and prescribing is limited to certain groups such as the clothing industry and mining houses where it is done in an occupational health setting, usually under the supervision of a full-time or part-time doctor. The results of the proposed trial [see next section], which essentially compares outcomes from these two approaches, will be very interesting.

"The scope of practice for nursing in South Africa is currently under review because of the national shortage of doctors, especially in the rural areas. I have no doubt that the planned ARV rollout will

influence this review significantly. Given the complexity of ARV treatment, I would still favour a supervised approach. Nevertheless, from our experience I have little doubt that both nurses and pharmacists are quite capable of playing a far greater role in managing HIV/AIDS in the community.

Nurse-led clinics

In Western Cape Province and in Johannesburg, South Africa, a clinical trial is being funded by CIPRA which will allocate patients with HIV randomly to a nurse-led clinic, backed up by access to doctors, or a doctor-led clinic, and compare outcomes in terms of health status and successful use of ARV treatment.

ORRELL: This is us! I have great confidence that the nurses are going to do as well as doctors, not the least because they are more likely in our context to speak the same language as the patients (which improves the education process and decreases the duration of the consultation).

CONRADIE: Our unit, the Clinical HIV Research Unit, is involved in the project as well. Two of our nurses are in control of about 200 compassionate patients - those receiving medication as a follow on their clinical trials, obviously under the supervision of a doctor. Once a patient is established on ARVs they do not need regular follow up by a doctor. Nurses can be trained to pick up toxicities and failure and only then refer to the doctor. We have used this model in our unit with no problems.

ROUX: I can't say much about nurse practitioners - apart from the fact that I'm in the CIPRA study you refer to in the Western Cape. I think that - for paediatrics at least, regimens should always be as simple as possible. The side-effects issue should be manageable with accessible supervision - it's my experience that nurses are appropriately more careful than doctors - hence more likely to pick up problems.

Treatment guidelines and roles

The scope for expanding the roles of healthcare staff in ARV provision will depend to a large extent on precisely what treatment is being delivered. Eventually, of course, we can all hope for simpler, more effective and reliable ARV treatments, which are as well-understood as first-line TB treatments. For now, however, there are choices to be made among imperfect drugs. One of the factors that will drive those choices is finding ARV regimens to suit the level of expertise and resources available to monitor and manage side effects in a particular setting.

GREEN: It is both reasonable and essential [to limit available regimens]. Partly this is because in Indonesia there is effectively only one affordable/available first-line regimen (nevirapine with a narrow choice of NRTIs), and no second-line or salvage regimen. Thus it is easy to identify the options, provide the limited guidelines regarding its management, and train doctors on its use. As Joep Lange frequently says, better to treat 100 and fail a few, than not treat the 100.

"Nonetheless, we do need better guidance on management of side effects, particularly nevirapine rash. Doctors tend to be scared of this, and are thus very conservative in treating through. Given that there is no alternative, more 'courage', based on better information, is in the patients' interest.

ORRELL: I think a scheduled approach, as used in the TB management programme, could work well for ARVs too. First line 3 drugs, then a second line 3, then you see a specialist if you choose to continue treating people who have failed the first two combinations.

BARIGYE: Given the tools and training most health workers are likely to be able to evaluate whether or not the drugs are working. If in doubt, the junior health worker can consult an expert. My biggest concern is about side effects, OIs, co-infections, immune reconstitution problems, etc. These may be a problem for junior health workers, especially when they present as emergencies. This will be even be more complex where there are various ARV combinations being used at the same time. Expecting junior health workers to be trained adequately to handle all the complications of various drugs may be too much. What can be done in my view is for countries to adopt 1st line, 2nd line and 3rd line combinations. The junior health worker will get used to one combination at a time.

PRABHU: Tuberculosis and the widely touted DOTS model with emphasis on drug compliance and treatment success are quoted as shining examples and replica of such systems are being readied for ARV drugs. But unfortunately it is not so simple. Stigma reduction, identification of cases, treatment based on sound clinical and laboratory judgements, treatment and management of life threatening opportunistic infections are also very important issues.

Peer-support as a principle and practice

It has often been found that the support given by patients to one another is of enormous value in securing high levels of adherence to treatment. This can be promoted, for example, by ensuring that waiting areas are comfortable and allow for friendly interaction and that a range of information materials are available for people to read and discuss and to prompt questions to health care workers.

In clinics which have pioneered ARV treatment, peer-support among patients has not emerged in a vacuum. There has generally been a discussion, involving community members, of the need for care and treatment and of the criteria by which people should have priority to receive treatment. Involvement of people with HIV in this discussion creates a climate in which people with HIV who are on treatment can be encouraged to get actively involved in delivering that treatment to others.

Self-help groups for people with HIV may be of great value in allowing people to come to terms with their diagnosis and its implications for their lives and relationships, before they have to deal with issues such as the need to take ARV treatment. Learning to attend a clinic regularly and establishing a relationship with trusted health care staff are likely to be additional keys to the successful use of treatment when it is needed. Some services make regular clinic attendance for several visits a precondition for starting on ARVs.

Organised support groups can take this principle one step further. Such groups can be designed as short training courses to encourage self care, primary HIV prevention, mutual support and effective use of available services. This is an opportunity for nutritionists/dietitians, trained pharmacists, sympathetic and knowledgeable religious leaders, and others who may be able to support people with HIV in a given setting to explain how they can be of most help.

ROUX: We tend to book mothers for follow-up visit in cohorts. The mothers get to know one another in clinic, they stimulate one another to ask questions. It's not so easy to find groups of mothers who live close enough to be supportive in the townships - hopefully this will change as care becomes more community-based. As it is, our mothers see one another every week. We have an income generating project (65 mums have earned a total of R 210 000 [USD 28,400] in a year) and they come to chat while finishing off their products and waiting to sell them.

GREEN: In addition, such groups can also play an essential role in encouraging religious (and other) leaders to become 'sympathetic and knowledgeable'. Given that funding for ART often comes from government or community, there is an urgent need for recipients to say 'thank you', and demonstrate the benefits that accrue from the donation. If those making decisions regarding such funding meet and become acquainted with PLHAs receiving ART, and see the dramatic change this often brings about, it becomes much more difficult to cut off such funding.

"Indeed, I have a feeling that if recipients of Global Fund drugs were to tour the US and Europe, talking openly and appearing on TV, we might find it easier to stimulate governments to increase their donations to the Fund.

"One drawback of peer support is that peers are not always well-informed. In addition, one case of poor response, or severe side effects, can have lasting negative effects.

One-to-one peer support

The system used in rural Haiti at the Clinique Bon Sauveur, where trained community volunteers known as 'accompagnateurs' supervise one of the two daily doses of ARVs taken by people with HIV, is an adaptation of an element of the DOTS system that is widely advocated, though not always easy to implement, for TB treatment.

In South African mines, where workers with HIV have been provided with ARV treatment, it has been found immensely helpful to identify 'treatment buddies' who can accompany and support the individual who has to take the treatment.

In other health care settings, in Asia as well as in Africa, involvement of an additional household member in treatment has been immensely helpful - some would say essential. For example, when a patient is seen by a doctor or nurse and has to remember several messages or instructions, having someone else there to discuss those messages with is likely to make them easier to remember and act upon.

GREEN: Most of these models of peer support are valid, if yet to be fully implemented. In Indonesia, we place great emphasis on empowerment of PLHAs in accordance with GIPA principles [Greater Involvement of People with AIDS]. Many PLHAs (including families) suffer, at least initially, from very low self-esteem, and this has major impact on health-seeking activities. The peer support group plays a major role in addressing this. In many cases, the first stage of development is to assist PLHAs to take control over their lives and their health.

"An empowered patient is more likely to be adherent, and to form a healthy partnership with health care providers. However, health care providers often prefer patients who just say 'Yes, Doc'.

"Lay treatment educators can play an important but largely ignored role (at least in Indonesia). People like me have much more time to study AIDS treatment than many doctors, who often have to cover a wide range of other diseases. We can also better understand the needs and limitations (language, understanding) of our community. Other sources of patient information booklets, pictures for illiterates - can also be valuable.

ORRELL: As I said before, our therapeutic counsellors are peers also HIV positive and from the same community as our patients. The majority of patients are willing to allow them into their homes and, as a doctor, [I find] they have really eased the burden of pre-therapy education.

RABKIN: Many MTCT-Plus sites are establishing peer educator programs. In Beira, Mozambique, patient 'activistas' assist with

supervision of antiretroviral therapy, outreach and home visits. In Lusaka, Zambia, peer educators provide patient education about HIV itself, the MTCT-Plus care and support programs, and about community resources.

BARIGYE: On the issue of adherence, I am of the view that more emphasis should be put on ensuring that most of the information required is provided generally to the public rather than from the clinic. Most peripheral units are usually understaffed and a multi-disciplinary team including counsellors is not going to be available soon.

Combatting social stigma

Social stigma and negative attitudes towards people with HIV or (in some settings) populations affected by HIV can remain a problem even where treatment is becoming available. Enabling staff to meet with people with HIV and understand their experience more fully is crucial in changing such attitudes.

Such training can do much to deal with the fears and anxieties of staff, but also has to be backed up by resources, for example, to enable universal precautions to be adopted consistently and prevent the emergence of stigmatising 'PLWHA precautions'. On the other hand, questions about the use of post-exposure prophylaxis after occupational injuries are also arising, and are not limited to the major treatment centres where PEP is currently most likely to be available.

Sometimes this stigma can transfer from people with HIV to those treating them.

GREEN: There are different challenges in places of low overall prevalence, but with concentrated epidemics. Doctors' AIDS case loads are quite low, they can't make a living from AIDS - partly because many patients can't pay! - but they are scared they will lose other patients if they become known as 'AIDS Doctors'. In addition, they have difficulty gaining experience and have even more limited time to learn.

"I do hope universal precautions are much, much, better adhered to in Africa than here in Indonesia, but lack of gloves, etc. result in them becoming 'PLHA precautions', extending stigma, and causing fear among HCWs.

Professional support and development

There is a clear and never-ending need for training and support to be given to health care staff who are taking on new roles or whose roles need to change to provide new services.

ORRELL: The needs are huge. I still think doctor training is key as I can't see ARVs being nurse-prescribed in South Africa just yet. Doctors must then take responsibility for the team and for training within and outside the team. Nurses need very similar training to the doctors functional ARV use, best done at clinics with access to people on drug so the lessons become reality. The Western Cape

has a mentorship programme for HIV training doctors and nurses come through the specialist HIV clinics weekly for eight weeks. This would work for ARVs too, with some initial theoretical input.

ROUX: The top training issues are:

For doctors: Acquire new insights and information through ongoing operational research. Sharpen skills, gain experience - able to go out to satellite clinics and train others.

For nurses: Upgrade expectations, work toward 'nurse practitioner' capacity and urge authorities to permit greater freedom to prescribe.

For counsellors: Refresher courses, keep skills and information up to date. Modify focus to deal with the real adherence issues as identified in the course of operational research.

For the pharmacist: Find your way into the clinic, take on a training and supportive role regarding adherence counselling.

GREEN: Briefly:

- Rational prescribing: doctors here in Indonesia are still prescribing monotherapy with tacit connivance by the drug companies for people who have no need of therapy
- Training to get back to basics and manage based on clinical signs, without expensive tests
- Training on the challenges of adherence, and how to identify and address these
- Provision of hotlines for doctors, similar to the Johns Hopkins Clinician Forum; email and telephone support
- Dissemination of information and particularly, news to health care workers. This is a particular challenge where many health care workers do not speak one of the 'standard' world languages. We rely on a wide range of English language sources for up-to-date information on new therapies, side effects, dosages, etc, etc. However, doctors in this country have no time to access this, and couldn't easily understand it if they did.
- Don't let's forget the ongoing need for OI prevention and treatment, plus palliative care, in our euphoria over ART.

about HATIP

A regular electronic newsletter for health care workers and community-based organisations on HIV treatment in resource-limited settings.

The newsletter is edited by Theo Smart (Cape Town) and Keith Alcorn, NAM's Senior Editor (London).

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