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# Helping to treat a global problem — as a paediatric HIV pharmacist

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More than 1,000 children in the UK are infected with HIV. This article describes the contributions of a paediatric HIV pharmacist in caring for these patients



Working as a paediatric HIV pharmacist has involved visiting hospitals in KwaZulu Natal, South Africa, to offer advice and share experiences

**T**here are over 1,000 children living in the UK with HIV (human immunodeficiency virus) infection. Approximately 70 per cent of these children live within the London region,<sup>1</sup> but the numbers living outside London are increasing. This article describes the specialist care available to these patients and their families from pharmacists and other health care professionals.

## Models of care

Since the main route of acquiring HIV infection for children is vertical transmission, when a child has HIV infection, it generally means that the mother will too, as may her partner and other children. A model of care that has evolved is the family clinic, where children with HIV infection, babies born to women with HIV infection and their parents can be seen in the same clinic. The first family clinic was established at St Mary's Hospital, London, where the multidisciplinary team includes paediatric infectious diseases consultants, adult HIV physicians, paediatric and adult nurse specialists, health advisers, psy-

chologists, dieticians and pharmacists. In many centres, there are close links to adult genitourinary or infectious diseases services.

Earlier this year, the UK's first clinic for teenagers who had been born with HIV infection was set up at St Mary's Hospital. This joint service, the "900 Clinic", was devised, and is run by, staff from both the paediatrics and genitourinary medicine departments and helps young people from north west London cope with the long-term aspects of living with HIV infection.

Historically, paediatric HIV services were developed in London at St Mary's Hospital, St George's Hospital and Great Ormond Street Hospital. Most children with HIV infection lived in or around London and were referred to one of these three specialist paediatric infectious diseases units. These units lead recognised networks in the north east, north west and south of London.

In the UK, approximately 80 per cent of children with HIV infection and babies born to mothers with HIV infection are of sub-Saharan African origin.<sup>2</sup> Many are asylum seekers. The stigma of having HIV infection often prevents families from getting the support they need. This problem is amplified in areas where, because of a low prevalence of cases of HIV infection, appropriate support services are not available.

The numbers of children with HIV infection living outside London is increasing. This is because of the rising number of people with HIV infection globally, recent patterns of migration and the dispersal of asylum-seeking families around the UK. There are currently no tertiary paediatric HIV centres outside London. Following wide consultation with stakeholders and regional workshops, the Children's HIV National Network (CHINN) proposed the development of a regional network structure for paediatric and perinatal HIV services throughout the UK. All service reviews have concluded that it is necessary to have a specialist paediatric HIV pharmacist as part of the core of the multidisciplinary team.

## Specialising in HIV

My initial enthusiasm for HIV pharmacy was sparked while undertaking a pre-registration research project about pharmacy interventions in HIV at the Jefferiss Wing at St Mary's Hospital, London. The project was awarded a prize from the HIV Pharmacy Association, which enabled me to attend an international HIV and infectious diseases conference. I went on to present feedback of that conference at a national HIV conference. The experience and knowledge I gained from these conferences left me moti-

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vated to pursue a career in HIV pharmacy. Following registration, I undertook a basic grade rotation at the Royal Free Hospital, London, where I worked in various specialties, including HIV, paediatrics, renal, production and medicines information and completed the certificate in clinical pharmacy. During this period, I continued my commitment to the HIV Pharmacy Association, which allowed me to keep up to date with current issues in HIV. I then accepted a position at the Royal Free Hospital as a senior HIV pharmacist. This position gave me the opportunity to apply my knowledge of HIV infection and to develop new skills and qualities essential for working with specialist health care professionals and, most importantly, patients with HIV infection.

The Royal Free Hospital infection and immunity department is a renowned centre of excellence for treatment of patients with HIV infection. Services, including those delivered by pharmacy staff, are continuously adapting because of the rapidly changing nature of HIV medicine and the increase in patient numbers. My role initially focused on clinical trials and the day-to-day running of the satellite pharmacy. It then involved an array of specialist duties, such as participating in consultant ward rounds, running a pharmacy adherence clinic, assisting in developing a home care service and training rotational staff. My experience with clinical trials is particularly invaluable because it has given me an in-depth understanding of the evidence base that guides treatment decisions in the clinic.

While at the Royal Free Hospital, and to improve my understanding of the care given to children with HIV infection, I attended monthly multidisciplinary team meetings for the management of 30 children. Many hospitals around England now have similar meetings, which are attended by visiting paediatric HIV consultants from one of the London networks (see earlier). Such meetings provide an excellent way for pharmacists from any background who have an interest in paediatric HIV to meet with other health care professionals and to become more involved with treatment decisions.

To pursue my interest in paediatric HIV further, I joined the Children's HIV Association (CHIVA) and completed a paediatric module as part of my clinical pharmacy diploma. Up until 2006 there was no formal

teaching in paediatric HIV. PENTA (Paediatric European Network for the Treatment of AIDS) set up a comprehensive online case study-based learning package with a follow-up residential course. The course is designed for consultants and specialist registrars but is open to anyone who has an interest in the area and is an excellent way to be learn both the fundamentals and the finer points of paediatric HIV care. Contact details for CHIVA and PENTA are set out in Panel 1.

I then became a paediatric HIV pharmacist at St Mary's Hospital. The transition from mainly adult to paediatric pharmacy was particularly challenging, but with the support of an experienced paediatric pharmacist, I developed the necessary skills to undertake my current specialist role. Our paediatric unit is one of the largest providers of paediatric HIV services in the UK. We offer integrated care, support and treatment to families affected by HIV infection. We adopt a multidisciplinary approach, starting in the antenatal period, and we are actively involved in research protocols to improve the care of HIV-infected children, enabling the earliest access to new therapies.

### — Issues for paediatric HIV patients

As in adults, managing paediatric HIV infection is focused around life-long antiretroviral treatment. Children have different immune systems, pharmacokinetics and tolerability of antiretrovirals from adults and teenagers, resulting in a difference in their response to treatment. Further details about these differences are set out in Panel 2, p54. Consideration of the capabilities of the care-giver as well as the child is also important.

Recent developments in the efficacy, tolerability and simplicity of antiretroviral therapy for adults have made good long-term adherence to therapy a real possibility. For example, Atripla, the first once-daily, single tablet antiretroviral fixed-dose combination (of efavirenz, emtricitabine, tenofovir) is set to be licensed in the UK this year to treat HIV infection in adults. Despite the reward of patent extensions to encourage pharmaceutical companies to undertake clinical trials in children, paediatric

## Panel 1: Useful websites and resources

- Children's HIV Association (CHIVA). Information available at [www.bhiva.org/chiva](http://www.bhiva.org/chiva)
- Paediatric European Network for the Treatment of AIDS (PENTA). Course details available at [www.ctu.mrc.ac.uk/penta](http://www.ctu.mrc.ac.uk/penta)
- Drug interactions and therapeutic drug monitoring. Available at [www.hiv-druginteractions.org](http://www.hiv-druginteractions.org)
- US Paediatric HIV guidelines. Available at [www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov)

## Panel 2: Issues that need to be taken account of when treating paediatric HIV patients

- Immunology — childrens' immune systems are still developing and they have a functioning thymus
- Patterns of HIV RNA — children generally have high viral loads that naturally decline as their immune system develops
- Pharmacokinetics — childrens' metabolic pathways are still developing
- Formulation tolerability — children require different formulations from adults and their needs change as they grow

atric HIV pharmaceutical development lags far behind that for adults and there are currently only a few antiretroviral preparations licensed for children in the UK. This means there is a great opportunity for specialist paediatric HIV pharmacists to influence treatment decisions, especially through applying expertise in formulation and pharmacokinetics.

### Day-to-day role

My role is ever changing but is always patient-focused. The core aspects of my day-to-day role are set out in Panel 3. Other aspects include:

- Reviewing new drugs — evaluating novel antiretrovirals for use in children (This necessitates applying adult clinical trial data to children, which involves an understanding of the pharmacokinetics and metabolism of antiretrovirals. Pharmacokinetic studies at St Mary's Hospital allowed the first child in the world to be treated with darunavir and etravirine.)
- Providing a medicines information service to UK centres and increasingly to Europe (via PENTA) and to South Africa (via CHIVA)
- Acting as member of London HIV consortium, which advises centrally on purchasing issues and gives prescribing guidance to London centres. (Subcommittees such as the drugs and therapeutics committee and cost saving committee allow pharmacists to influence choice of therapy.)
- Acting as a member of CHIVA committee — as the first pharmacist on the executive committee of CHIVA, I am currently expanding the role of pharmacists and commenting on official documents referring to drugs

- Providing adherence support — includes advising about, eg, tablet swallowing
- Assisting with clinical trials

### Experience in KwaZulu Natal

During my time at St Mary's Hospital, I have also been involved in the CHIVA/KwaZulu Natal Support and Mentoring Initiative. This is a collaboration between CHIVA, the KwaZulu Natal Department of Health and the University of KwaZulu Natal. It supports the National Antiretroviral Roll-Out Programme, which began in 2004, to provide universal access to treatment for all HIV-positive South Africans.

Antiretroviral regimens are complex and require patients, care-givers and health care workers to administer them responsibly. The absence, until recently, of antiretrovirals in the public health system of South Africa has resulted in a lack of experience and confidence in prescribing and monitoring these treatments, particularly for children.

The health care workers in KwaZulu Natal are well trained and South African treatment guidelines are well thought out and comprehensive. However, the practicalities of managing children on medicines and the ways of dealing with pitfalls encountered are not easily learnt from academic texts or even courses, and nothing can substitute for experience gained over time.

On visits to KwaZulu Natal, some of the activities I and other paediatric and HIV pharmacists became involved in include:

- Discussing cases — talking to doctors, nurses, pharmacists and health care counsellors about clinical situations and their management, either one-to-one or in a wider group session
- Attending clinics
- Giving workshops and presentations
- Attending ward rounds — providing guidance and reassurance to prescribers and other health care professionals (These also provide an opportunity to develop your own skills and see a greater variety of paediatric HIV-related infections and in much greater numbers than in the UK.)
- Visiting rural centres away from towns (This gives an eye-opening insight into the care of patients without the comfort or bureaucracy of a large hospital environment.)
- Meeting with "high level" health care providers, such as local government representatives and non-government organisations

### Treatment advances

The most exciting treatment developments in paediatric HIV are advances being made in the developing world in formulating

## Panel 3: Day-to-day role of paediatric HIV pharmacist

- Provision of a specialist clinical pharmacy service to paediatric HIV family clinic patients (adults and children)
- Inpatient service to HIV and infectious disease patients and clinical support to HIV patients on neonatal ICU (intensive care unit), paediatric ICU and obstetric wards
- Multidisciplinary meetings about the management of patients in our network
- Patient meetings and perinatal meetings to decide on complex regimens before prescribing them

child-friendly antiretroviral combinations, such as fixed dose preparations. These are generally being led by Indian generics manufacturers whose products are now available throughout India and sub-Saharan Africa.

CHIVA helped initiate an internationally endorsed joint policy statement, "Increasing antiretroviral access for children with HIV", to improve the availability of more child-friendly dosage forms.<sup>3</sup> Dispersible, melt formulations and "mini pills" appear to address the difficulties in masking the taste of liquid dosage forms.

The availability of patent extensions has meant more clinical trials of antiretrovirals for children are being conducted, but some of these do not appear to be of the quality and type hoped for.

### Conclusion

Providing pharmacy services to children with HIV infection is a specialised role, but one that is increasingly needed, given the global rise in incidences of HIV infection. In the future, it is hoped that more child-friendly formulations of antiretrovirals will be licenced in the UK. In the meantime, advice from paediatric HIV pharmacists, who understand aspects of paediatric care, drug formulation, and the pharmacokinetics and metabolism of antiretrovirals, is invaluable.

### References

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