

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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Aims and Scope

HIV Nursing has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

HIV Nursing is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day to day matters affecting the lives of patients.

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Storm in a Cornish teacup?

Ian Hodgson

School of Health Studies, University of Bradford

St Ives, in south west England with a population of 8000, is best known as a holiday resort. However, on 5th May 2006, the local Primary Care Trust (PCT) released a press statement confirming a cluster of new HIV infections in the region, all possibly relating to the activity of one man. The statement confirms that people could have been infected in the last 6–8 years 'in a wide range of age groups, from young adults through to men and women in their fifties, who have had unprotected sex'. Those at risk were called to come forward for testing and the helpline received 200 calls in the next 3 days, and numbers attending for HIV tests are increasing steadily. No figures have been released yet regarding additional cases of HIV infection.

The decision to go public was made because of fears by the PCT that it would be unable to trace all possible contacts in time to prevent further infections. Not surprisingly, this received national attention. Local reactions ranged from people being 'horrified' to the more pragmatic, such as 'it won't matter to most people unless they're the one that's affected.'

As healthcare workers involved in HIV care, what can we learn from this?

First, the pressures on clinics in areas of relatively low HIV prevalence are clearly highlighted. Contact tracing is always a complex and convoluted process but in the case of HIV, where it is essential to ensure infected people and those most at risk are *aware* of their circumstances, smaller health centres will inevitably be stretched beyond their capabilities, hence the PCT deciding to go public. Second, 'it will not matter to most people' appositely describes the excessively idiosyncratic approach to risk assessment adopted by many people – the tendency to *overestimate* risk in certain circumstances and *underestimate* it in others. Academic papers confirm this worrying approach to risk assessment – an awareness of *how* HIV (for example) is spread but an assumption that *this person* will not be a carrier.

Third, simply, why are we surprised at this cluster? Numbers of new cases of sexually transmitted infections in the UK continue to climb and teenage pregnancy rates remain high. We seem a country determined to refuse proper and mature consideration of our sexual behaviour.

The sudden increase of the incidence of HIV in St Ives will inevitably have an impact on the region but is also a symptom of the larger British malaise: a staggering naivety concerning sexual safety.

Expect more clusters over the coming years.

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Child protection issues in HIV-positive children

Margaret Clapson

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Introduction

'Every child living in this country is entitled to be given the protection of the law, regardless of his or her background.'

The Victoria Climbié Inquiry Report, 2003.

Dealing with families or carers about concerns of child abuse or neglect is never easy or emotionally comfortable, but it is an unavoidable reality for healthcare professionals involved with children. Child protection has become more prominent since the sad case of Victoria Climbié in 2000 and most institutions now make child protection awareness training mandatory for all NHS staff that have contact with children [1,2].

Child abuse and neglect, even serious cases, often go unreported. Case studies and research cite several common barriers to reporting: fear of retaliation from abusive parents, trepidation at worsening the child's situation, apprehension at being wrong about the abuse and possible litigation, unease at intruding on family privacy and limited time or resources [3]. However, the consequences of abuse are well known, often leading to severe physical and psychological damage, long-term impairments and (in extreme cases) death [4]. Children remaining in abusive environments can have high levels of anxiety, negative self-image and demonstrate aggressive, self-destructive and suicidal behaviours [5].

HIV-positive children are under constant medical care and the professionals involved continue to have regular direct contact with the parents for many years. These health and allied professionals usually have a long history with the family, often dating from the initial diagnosis of the child, and continue to share in many of the family's life events.

Owing to the stigma and discrimination that surrounds HIV, medical and allied healthcare professionals are often the only support network many families choose to have, with regard to knowing the family's HIV status.

This familiarity can make professionals reluctant to report concerns when difficulties arise over parenting issues, children's rights and what are perceived as the best long-term interests of the child. There is anxiety to maintain a good relationship with the family and about the discomfort child protection concerns bring.

Children Acts and UK law

The Children Act 1989 put into place the requirements needed to achieve the best interests of children and discusses the implications for policies, procedures and practice [6].

It also introduced the concept of significant harm and the duty, which is expected of any authority or person, to make enquiries if there is reasonable cause to suspect a child is suffering, or is likely to suffer, significant harm. Harm is defined as ill-treatment or the impairment of health or development, the latter especially pertinent to paediatric HIV [6].

The Act changed the emphasis from the rights that parents had over the child to the responsibility parents have to demonstrate adequate parenting skills. It also ensured the well being of the child does not come second to the wishes of the adults [6].

In 1999, in what is known in HIV circles as the Camden baby HIV test case, the issue of parental decision over a child's best interests was challenged in the High Court. This was the first case of its kind to argue for HIV testing of a baby born to an HIV-positive woman, looking at what was the in the child's best interests with regards to present and future health status. If the baby were to test positive for HIV then the focus would shift to preventing opportunistic infections and deterioration of the immune system.

The mother, who was diagnosed in 1990, was sceptical about the conventional medical approach to HIV and rejected advice given during her pregnancy regarding interventions to reduce the vertical transmission of HIV. The baby girl was born by vaginal delivery and breast fed. The parents, contrary to repeated medical advice, then refused to allow the child to be tested for HIV. The parents stated that there was no risk of HIV transmission to the baby during the pregnancy, vaginal delivery or breast feeding, and that the mother would continue to breast feed the baby.

The outcome of the case was that the baby had to be tested for HIV. The judge stated the child's rights to life, to the highest attainable standard of health and to facilities for the treatment of illness. The father said he regarded the rights of a tiny baby as subsumed within the rights of the parents but the judge stated clearly that the father was wrong in this assumption and that the baby had rights of her own [7].

Most parents, accustomed to being the decision makers in matters regarding their children, usually become disempowered in litigation. In child protection cases in which parents neglect or fail to care adequately for their children, more effort is needed to explain the responsibility these adults have for their children. This would facilitate a better understanding of children's rights and assist parents to participate collaboratively with others in determining what services should be provided to achieve the best outcome for the family and child [8].

Looking at HIV

Although the disease is currently incurable, early diagnosis and mounting knowledge about HIV and the timely use of antiretroviral therapy (ART) have greatly improved HIV-associated morbidity and mortality. Successful detection of HIV in pregnant women, which is due to the uptake of universal antenatal HIV testing and a corresponding reduction in perinatal transmission, has reduced the number of children that are born with HIV in the UK [9].

Child protection concerns have occurred over breast feeding, refusal to test the baby, non-administration of prophylactic medication and non-attendance for follow-up of these babies, whether they are infected or of indeterminate status.

Most paediatric HIV infection is acquired by mother-to-child transmission. The holistic care of children infected with HIV, which is now treated as a chronic disease, is complex. Guidelines in the UK concerning which ART to choose for children (and when to use it) were first laid out in the 2002 Paediatric European Network for Treatment of AIDS (PENTA) guidelines and updated in 2004 [9].

Children with HIV have to live with particular complexities including, for example, stigma, secrecy, disease management, the life-long toxicity of antiretroviral therapy, the development of sexuality and relationships and tentative expectations for the future.

Adolescents with HIV are often familiar with the practical aspects of their treatment but can lack a deeper understanding of the reasons for therapy or the risks that HIV poses to their health. They may manifest delayed development of personal maturity, and occasionally resort to therapy non-compliance to manipulate their parents or carers [10,11]. The refusal of a young person to comply with his or her clinician's HIV management recommendations, despite parental support for these, is currently creating very difficult and challenging ethical problems for all involved.

There remains, although currently to a lesser degree, the difficult issue of disclosing the HIV diagnosis to young people. This can be a problem because it involves awareness of the parents' HIV status [11].

However, the reluctance of some parents to disclose their HIV status to a cognitively competent child over 10 years of age could have huge legal implications. There are many understandable compounding factors which make disclosure difficult for families. Great care is needed to balance duty of care, parental anxieties and respect for the young person's legal rights to autonomy, decision-making and informed consent [10,12].

To my knowledge, there have not yet been any cases in which a minor has been convicted of sexual transmission of HIV to another minor in the UK. However, if a sexually active adolescent is unaware of his or her own status, who else could be held accountable for transmission of HIV; the parents or the healthcare professionals who manage the adolescent's care?

Ethnicity and culture

HIV and AIDS disproportionately affect African communities in the UK. The 2001 census established that there were just over 480,000 people in England who described themselves as black African. This is a culturally diverse population with many varied ethnic identities, languages and religions [8].

Many traditional practices and beliefs remain prevalent among these communities, especially regarding child-rearing practices. There is a wide spectrum of acceptable parenting styles that influence the pace at which children gain independence, and cultural expectations of age-related levels of autonomy can vary [4,10].

Cultural norms can differ considerably between communities and families and there is a danger of making assumptions. Understanding and accessing social and welfare services in the UK can be difficult for asylum seekers and immigrant families from ethnic minorities, particularly if English is not their first language [2]. Racism is an additional source of tension and needs to be identified and dealt with immediately, because the 'fear of being accused of racism can stop people acting when otherwise they would' [1]. Regardless of any child's cultural background, there can be no rationalisation for not taking adequate measures to protect a child because of the HIV status of the family.

Particular consideration needs to be given to use of appropriate legal interventions in cases in which the family could remove the child from the UK to evade the involvement of agencies with safeguarding responsibilities [4]. This is a growing concern with the mounting evidence of the use of exorcism and the conviction of the African Charismatic and African Initiated churches that demonic or evil possession is present in children.

Given recent advances in paediatric HIV management and evidence of the effectiveness of ART, it is not acceptable to allow families that are rigidly opposed to therapy to withhold this from the

child [9]. When time permits, it may be possible to refer to neutral and mutually acceptable third parties to assist with negotiations. However, having exhausted all avenues to reach a consensus decision with the family, healthcare professionals involved will need to request social services to act as the advocate for the child [14].

It should be standard practice to discuss the need for a referral, and to get the parents' permission if possible, unless by doing this the child is placed at greater risk of significant harm [4]. Even if permission is not forthcoming, parents should be fully aware that the healthcare professionals have concerns.

In my clinical HIV experience over the past decade at Great Ormond Street Hospital for Children, there have been few problems of severe non-compliance with medical care, advice or treatment that have led to Child Protection referrals. Where referrals have occurred, any problems have been resolved in court, all with positive outcomes for the children involved. Most of the cases have been over refusal to give ART or non-adherence to it, and the court can grant a specific issue order that is designed to deal with one-off decisions that need to be taken on behalf of the child [15].

Social services

The Children Act 1989 lays down the duties of local authorities to work together to safeguard and support the welfare of children in need. Social services have the lead responsibility for children about whom there are welfare concerns.

The introduction of a statutory assessment framework in 2000 required that all agencies with responsibility for services to children, including social, health, education, police, probation and voluntary sector services, work together to protect children [16].

Medical responsibility

It is recognised that an HIV-positive child or young person's paramount interests are not restricted only to his or her best medical interests, but also encompass wider issues such as societal, spiritual and welfare needs.

When difficult decisions in paediatric HIV care are needed, the wider involvement of all healthcare team members and the child's family will enhance the quality of the final decision [14]. Respectful and careful assessment of competence is needed to make medical decisions for children when confronting varying cultural and family expectations.

Clear communication is necessary and, pending an agreed decision, the medical assessment of the level of health risk to the child is important. In most instances, these cases can be divided into high- or low-risk categories, the most difficult category being

a young person at high risk of serious disease/death, yet mature and cognitively competent, who is refusing treatment. This causes enormous ethical and moral dilemmas for those responsible for the medical care, and obtaining expert psychological advice is essential [10].

Conclusion

All hospital and community medical staff and other allied health professionals should be alert to the possibility of child abuse or neglect. Sound professional practice involves making judgements that are supported by research evidence and clinical experience. HIV clinical nurse specialists, in my opinion, have a particular role in identifying these child protection issues early, as we often have more regular contact with the families. However, it can be difficult for nurses to initiate decisions on their own in cases that involve managerial and organisational ethical issues [10].

Working closely with HIV-positive families to prevent the escalation of any child protection concerns is essential. However, familiarity must not prevent healthcare professionals from bringing child protection issues to the attention of the appropriate services, as this will compromise professional accountability and veracity. When there is conflict between the opinions of medical professionals and of parents or those charged with legal proxy for incompetent minors, the final responsibility for the best interests of a child or young person remains for the courts to decide.

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Clinical trials for a preventive HIV vaccine in adolescents

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Introduction

Globally, HIV/AIDS is predominately a heterosexually transmitted disease, although there are significant areas where the epidemic is driven largely by intravenous drug use or where infection is more prevalent in populations of men who have sex with men. An important target for ending the HIV/AIDS epidemic is preventing heterosexual transmission. To accomplish this most effectively, a successful preventive vaccine should be introduced into a public health campaign for people who are sexually active or have not yet initiated sexual activity. In the populations hardest hit by the epidemic, prevalence of HIV infection increases dramatically in the mid to latter part of adolescence (i.e. 15–19 years of age), which is co-incident with the onset of sexual activity. Therefore, a public health campaign that is directed at early to mid adolescence, before sexual activity begins in most individuals, would target an appropriate population to affect the epidemic.

However, such a public health campaign could not be undertaken without first studying prospective vaccine candidates in the target population to determine their safety, activity (i.e. immunogenicity) and potentially, their efficacy in that population. Therefore, as more promising HIV/AIDS vaccine candidates enter the product pipeline, we must pave the way for clinical trials in adolescents, as well as in adults. There are many challenges to research studies in adolescents with a vaccine to prevent a sexually transmitted disease, but it is important that they be overcome. Otherwise, we will have a successful vaccine that cannot be delivered to an important target population

because of a lack of relevant data to support its safe and effective use. Failure to deliver a successful preventive HIV/AIDS vaccine to adolescents at the earliest opportunity would be a public health and ethical tragedy.

The need for an HIV vaccine

The high incidence of HIV/AIDS is well known. In 2005, there were 4.9 (4.3–6.6) million new infections and 3.1 (2.8–3.6) million deaths from AIDS. Also in 2005, 40.3 (36.7–45.3) million people were living with HIV; of these 17.5 (16.2–19.3) million were women aged 15–49 years [1]. But how many of those women are 15- to 19-year-old girls (mid- to late adolescents)? And just how many of this age group are at risk? Statistics on sexually activity, marriage and parity before the age of 15 are available from the Joint United Nations Programme on HIV/AIDS (UNAIDS) for 2000–2001 from a survey of 15- to 19-year-old girls in several countries. Some results from sub-Saharan Africa, the hardest hit region, are presented here. In Mali, in 2001 15- to 19-year-old girls who were surveyed reported that by the age of 15, approximately 25% had initiated sexual activity, approximately 18% were married and approximately 5% had a child. In Ethiopia, approximately 15% were married and/or had initiated sexual activity before 15. In Malawi, more than 15% had initiated sexual activity before 15 and approximately 5% were married [2].

HIV-prevalence data are reported in age ranges and by gender. For 15- to 24-year olds, in many countries, the prevalence of HIV in women is far greater than that in men of the same age range. In Kenya, >5% of 15- to 24-year-old women were HIV

infected in 2003, whereas <2% of men were infected. In Zambia, >10% of young women and <4% of young men were infected in 2001–2002. In South Africa, >15% of young women and approximately 5% of young men were HIV infected in 2003. And finally, in Zimbabwe, approximately 18% of young women and approximately 5% of young men were infected in 2001–2002. These statistics reflect the fact that adolescent girls and young women often first take part in sexual activity with older men for various cultural and socio-economic reasons. After they have been infected by their older partners, they could transmit the infection to males in their peer group. Thus, the prevalence in young men lags behind that in young women. Sometimes this initiation of sexual activity in adolescent girls is by choice but sometimes by force, which the adolescent does not choose or cannot control. In a survey in 2000 in South Africa, when sexually experienced girls were asked whether they had ever been forced to have sex, 39% reported that they had. In many of the parts of the world where the HIV/AIDS epidemic hits hardest, women's rights and socio-economic status are not equal with those of men. In these regions, economic subsistence and social status are often linked with women's reliance on men and with their fertility and sexuality. These factors are believed to be among those that drive these statistics [2–4].

The hope for an HIV/AIDS vaccine

So where are we with regards to developing a preventive HIV/AIDS vaccine, so that more can be done to stop the epidemic? There are so many scientific challenges to the development of an HIV/AIDS vaccine that progress has appeared inexorably slow. Many, if not most, of these challenges have been outlined in a recent commentary [5]. Among these are geographic and genetic variability, rapid mutability of the virus, lack of identified immune correlates of protection, imperfect animal models of disease and the fact that HIV integrates into the host genome and targets the host immune system. Despite the challenges, more than 80 vaccine candidates have entered clinical trials around the world over the past 20 years. These have ranged from monovalent subunit vaccines (similar in design to the hepatitis B vaccine) to novel non-replicating expression vectors (e.g. DNA plasmids, replication defective adenovirus vectors, alphavirus replicons or poxviral vectors that do not replicate in mammals) that express multiple HIV antigens from one or more clades of HIV. The pre-clinical and clinical pipeline has been reviewed recently by Rodriguez-Chavez *et al.* [6].

Currently, there are three candidate vaccine strategies that have advanced into on-going phase II or III clinical trials. A phase III efficacy trial is being conducted in Thailand in a collaboration between the Royal Thai government, Mahidol University, sanofi-pasteur, Vaxgen, Walter Reed

Army Institute of Research (WRAIR), US National Institute of Allergy and Infectious Diseases (NIAID) and the Henry M. Jackson Foundation for the Advancement of Military Medicine. This is a community trial being performed to determine whether immunisation with canary pox vector (ALVAC-HIV B/E) priming followed by an AIDSVAX B/E (bivalent gp120 subunit vaccine candidate) boosting can protect Thai volunteers from HIV infection. In addition, if vaccinated individuals do become infected as a result of risky behaviour during the trial, those individuals will be monitored for their control of viraemia to determine whether immunisation resulted in a difference between these individuals and placebo recipients who become infected during the trial [6,7].

A phase IIIb pilot efficacy trial (referred to as a test-of-concept trial) is being conducted in North and South America and Australia, in collaboration between Merck, the HIV Vaccine Trials Network (HVTN) and NIAID. This trial is to determine whether immunisation with adenovirus type 5 vectors expressing HIV clade B gag, pol and nef proteins can protect against infection or control viral load in those vaccinated who become infected as a result of risky behaviour during the trial. Because this vaccine candidate does not contain the viral envelope, it cannot elicit neutralising antibodies, which target the viral envelope, so it is the first pilot efficacy trial of an HIV vaccine candidate that is anticipated to function through cell-mediated immunity, rather than through neutralising antibodies [6,8].

A trio of phase II and phase I safety and immunogenicity trials is being conducted internationally in North and South America and east and southern Africa, in a collaboration between the Vaccine Research Center at NIAID, the HVTN, the International AIDS Vaccine Initiative (IAVI) and the US Military HIV Research Program (USMHRP). These operationally harmonised trials are being carried out in a trio of trial networks to determine whether immunisation with multi-clade multi-gene (*envA*, *envB*, *envC*, *gagB*, *polB* and *nefB*) DNA plasmid vectors priming followed by multi-clade multi-gene (*envA*, *envB*, *envC*, *gagB* and *polB*) adenovirus type 5 vectors boosting is safe and immunogenic in the different populations (in the Americas and Africa). These vaccine candidates were designed to be globally relevant, as clades A, B and C (and D, which is closely related to B) are represented in approximately 90% of the world's infections [6,9].

So far, most completed HIV/AIDS vaccine trials have been phase I trials. phase I vaccine trials are generally conducted in healthy low-risk individuals to ensure that initial safety data are collected with minimal 'noise' and to ensure minimal risk to trial subjects. Thus, adolescents (under the age of 18 years) have not yet been involved in HIV/AIDS

vaccine trials. However, as more and more promising HIV vaccine candidates move from pre-clinical to phase I trials to phase II and III trials, trials in populations more reflective of the actual target of a public health intervention must be planned and executed. A WHO-UNAIDS Expert Group met in a consultation in Lausanne, Switzerland in August 2004 to discuss 'gender, age, and ethnicity in HIV vaccine-related research and clinical trials' [3]. A similar consultation focused on adolescents sponsored by the WHO-UNAIDS and the African AIDS Vaccine Programme was held in Gaborone, Botswana in March 2006 on the 'inclusion of adolescents in HIV vaccine trials'. Simultaneously, willingness-to-participate studies and epidemiological surveys are beginning or continuing in many countries to prepare populations for vaccine trials.

The challenge

Nevertheless, there are many challenges to clinical trials of vaccine candidates intended to prevent sexually transmitted disease, particularly HIV/AIDS, in adolescents. Among these are real and perceived risks of stigmatisation, social harms, problems arising from vaccine-induced seropositivity, ethical and legal frameworks (e.g. age of consent and parental permission), varying international regulatory requirements and proscriptions on research in children and operational complexities. These challenges are numerous and complex and are detailed elsewhere (Jaspan *et al.*, HIV vaccine clinical trials in adolescents: DAIDS position paper, unpublished data).

Perhaps chief among the concerns is that being in a vaccine clinical trial will lead participants to believe they are protected and might encourage risky behaviour, including initiation of sexual activity in previously abstinent adolescents. This concern of disinhibition (increase in risk behaviour as a result of the false impression of being protected, or the 'therapeutic misconception') was also voiced for adult phase III trials of a vaccine strategy that unfortunately ultimately failed to demonstrate protection. Both of the completed phase III trials for products that did not demonstrate efficacy were successful at addressing this concern in the context of clinical trials conducted with extensive counselling on HIV risk and behaviour modification. In fact, overall risk behaviour among participants decreased over the course of those trials. [10,11]. However, whether this concern would be heightened in an adolescent population still requires addressing. Lessons learned from those trials and others that are ongoing will serve as a model for addressing this concern in HIV/AIDS vaccine trials that will eventually include adolescents.

Lessons have also been learned from the conduct of trials of vaccines to prevent other sexually

transmitted diseases (human papilloma viruses and human herpes simplex virus type 2) that included adolescents [12]. So, perhaps the main challenge will simply be implementing the lessons learned and overcoming the various hurdles to permit safe and ethical trials of promising HIV/AIDS vaccine candidates and strategies to be conducted in adolescents around the world.

Conclusion

Without clinical data in populations that would be the intended target of an HIV/AIDS vaccine public health campaign, such a campaign would be needlessly delayed or never occur at all. To miss the opportunity to protect children before they become at risk of a disease, when there is a safe and effective vaccine that could prevent it, would be a public health tragedy that we cannot afford. Thus, we must be prepared to meet the challenges and ensure that at-risk children have the same protection in the same time frame that we are aiming to achieve for adults at risk of HIV/AIDS.

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Fostering an HIV-positive child: a personal experience

Jackie Ferguson

Foster carer and paediatric nurse

Initial meeting with Paul

Paul first came to us as a foster placement in November 1996 when he was 11 years old. His background was ambiguous but included the following details:

- He first appeared in primary school half-way through year six from central Africa with very little English.
- The opportunity to repeat year six was offered but he wanted to move with his friends to secondary school and this was facilitated.
- His first of many exclusions from school was in October 1996 for violent behaviour, despite the Education Statement process¹ from which he received maximum support.
- He was placed on the child protection register under the categories of physical and emotional abuse.
- He received a severe beating from his mother and stepfather, resulting in them being cautioned by the police.
- He regularly absconded from home and his mother felt he was out of control.

Paul quickly settled into our home with me, my husband, three birth sons aged 12, 9 and 3 years, two teenage foster daughters and a large extended family. The purpose of Paul's placement was to assess his needs and plan his rehabilitation for returning home. Paul's placement was certainly challenging but we have not regretted any of it.

¹ Formal Local Authority process resulting in recognition of the special educational needs of a child by provision of specific additional resources for that child to meet those needs.

Paul's behaviour pattern

Two to four times a week Paul would 'just play with my mates' or meet someone and maybe go home with them but, ultimately, not come home. As his foster parents, this behaviour was challenging to cope with and characterised much of his adolescence. Paul also stole from school and home. We tried collecting him from school and escorting him home but he developed avoidance techniques. The absconding behaviour meant we compiled a large file of missing person reports with the local police.

Although relatively small in stature, Paul often got into fights within the home and tried to bully the younger children, particularly his 9-year-old roommate. He required almost constant attention and we found it best to keep him as busy as possible. Paul's behaviour eventually became too much for our family so a planned move to another carer took place in July 1997. Unfortunately, this only lasted 6 days and Paul was returned to the care of his aunt and the little sister he really missed.

Paul became a missing person in around September 1997 and was eventually traced to relations in France through international social services and Interpol in August 1998. His social worker visited him in France and found he was happy and well, although not yet in school. Paul was given the option of staying in France or returning to London and he opted for London. The French family then mentioned that they knew how Paul's parents had died. Indeed, they had tested Paul, without his knowledge or consent, and found him to be HIV positive.

As a foster parent, this was quite a bombshell. Despite my paediatric nurse training, I had to stop and think 'have my children been at any risk during the year'?

On returning to London, Paul had two placements that broke down within a month. We then agreed to his request that he should return to us to allow social workers, therapists and medical staff to explain everything and retest him.

We experienced a rollercoaster of thoughts and emotions as we tried to carry on with our 'normal' life. I would lie awake thinking about the questions he might ask and rehearse what I would say. This was also a new situation for the social workers, as Paul was the first HIV-positive looked-after child (LAC) in the local authority. Therefore, our main support was from the nursing and medical staff at the hospital.

Paul disclosed his HIV status to my eldest son (who was also 13) on the day his status was confirmed. He just had to tell somebody.

And so, the long struggle of life continues

We entered a stage during which our family life revolved around Paul's hospital appointments, blood tests, viral load measurements, CD4 cell counts, regular medication of antibiotics and antiretrovirals. Our desire to ensure that Paul was not discriminated against because of his status both as a LAC and someone who was HIV positive was fierce. Paul's old school took him back but at the time he had the reading and comprehension skills of a 7 year old, and he was never able to take his GCSEs. His behaviour remained unchanged and he often 'forgot' to come home, so despite talking, agreements, cajoling or promises, our file of missing person reports grew.

Paul is immature both physically and emotionally for his age. Consequently, we have frequent and lengthy conversations concerning girls, sex, drugs and gangs. It was felt that his learning and behavioural difficulties, depression and suicidal ideation were a consequence of the death of his parents, loss of his native country and language, and a frequent change of carers.

Our joint (Paul and ourselves) interactions with the system continued. We had meetings and reviews, and we were trying to prevent school exclusion and planning for his future constantly. Discussions about Paul's options were frequent. Paul wanted to stay with us on a long term basis, stating he was happy with his situation. Therefore, we had increased and intense communication with a large circle of professionals. Every day it was a challenge to occupy Paul, almost a battle. We facilitated DJ-ing, football and holidays. Paul's immigration status was uncertain and after a long struggle and a judicial review, he was given exceptional leave to remain in the UK.

Disappearance

Paul disappeared for over three weeks and we were frantic. Prior to this, his absences were no longer than two days. Searches of the area and media involvement yielded nothing but Paul eventually presented himself in a local social work department. Consequently, his doctors decided to stop the antiretrovirals because they were worried about Paul's development of resistance.

We decided we needed respite support, so Paul went to carers outside London. However, it only lasted a few weeks as he developed a lump on his neck, which was diagnosed as lymphoma in November 2000.

Problems arose concerning permission for medical treatments. As foster carers cannot make such decisions, a senior social services manager who had never met Paul made his health-related decisions. Delays meant that Paul gave his own permission for some treatments. After 6 months of chemotherapy, the lymphoma went into remission.

Leaving care team

Once aged 16, all LAC are transferred to a leaving care team (LCT) of social workers. Paul became keen to move to semi-independence. It took a great effort to locate suitable accommodation with 24-hour supervision, close to college, to us, to friends and of course the issue of his confidentiality still applied – who should his status be disclosed to among the unit management (particularly given the high staff turnover)? We equipped Paul with his necessities and moved him in. He visited us quite often and, although sometimes he looked rough and his friends dodgy, we kept the door open. He seemed to come less often for dinner but more often for money. He stole while visiting, emptying my purse and taking CDs or computer games. He told me he was taking his medication and going to medical appointments but I could not confirm this.

By the time Paul was 17 years old, his offending behaviour had resulted in his detention in Feltham Young Offenders Institute (YOI), which was then included in our list of places to visit. Paul phoned and wrote often and reminded us to send postal orders and bring clothes. Throughout, we reminded the LCT of their responsibilities to Paul. He had two short spells on remand, and was sentenced. Eventually, he was released to another semi-independence unit. He then returned to Feltham YOI on remand for almost a year, but then the case was dropped and he was released a week before the court hearing. The LCT instructed Paul to present himself to the homeless families unit and tell them what was wrong with him. So much for confidentiality. Although Paul was entitled to a flat as a person that was 'looked-after', it did not happen. Paul still cannot read or write, although this improved in prison.

It took 3 months to get Paul's things out of local authority storage so he could claim benefits. We talked about his medication (which he promised he was taking – but was not, in case his mates saw and asked awkward questions).

Then came the dreaded call again, this time the solicitor said it was very serious. He would get a long sentence and he was back on remand but to a very different prison. Then a friend told Paul that someone told him that Paul's girlfriend is pregnant. Paul could not contact her because the police had his phone and he was not even sure of her full name or address. What could I do?

We almost had a row at the next visit. So then it was more letters, sending clothes, a Playstation with games, bed kit and postal orders. The visits to the new prison always took all day – and involved surrendering your fingerprints, the taking of photos and quite intimate searches. We had to keep going and the local authority was not interested because Paul was now over 18 and his relatives would not contact him. In the autumn of 2005, Paul received a sentence of 7 years.

Prison medical care

When he got to Feltham YOI, the nurse phoned me, on Paul's suggestion, for information on medication and to find out which hospital he was registered with. He was always happy about how the medication was given to him and with the general care he received. There were sometimes problems visiting his specialist and oncologist due to lack of escorts and the lack of privacy, with officers refusing to leave the room and the doctors refusing to see the patient with officers present.

Paul was left without any medication at the new prison, in spite of my reminders and complaints. The situation was only resolved when Paul had to return to Feltham YOI at which time the Feltham nurses sorted it out within 24 hours, only for the

medication to stop again, once Paul returned to the prison. It was restarted only after I asked them once again to contact the nurses in Feltham for the relevant information. Paul had some blood tests and visited a hospital outside London, which had no records and did not know which hospital he was registered with. It all seems so depressingly random. Paul will be remaining at his current prison until he is 21 years old later this year. He is really not happy, complains that the staff are racist and does not trust the nursing staff.

I hoped the medical care would improve once public prison medical provision transferred to Primary Care Trusts in April 2006.

The future

The future looks bleak for Paul. As a LAC and a young black boy, the statistics were stacked against him, and his infection with HIV has greatly compounded this.

There are approx 78,500 LAC in the UK, of whom about two-thirds live in foster care. Almost 60% of those in care leave school with no qualifications at all. Over 25% of prisoners were in care as children and 25%–33% of rough sleepers were in care [1].

I found no statistics on the prevalence of HIV among LAC in the UK, but in parts of Africa, including the area from which Paul originates, the antenatal prevalence of HIV is so high that 10%–20% of all children have been vertically infected with HIV [2]. We often wonder whether we could have done anything differently. Probably; but we did our best.

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Guidelines for the testing of looked-after children at risk of blood-borne infections

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Introduction

Despite the success of prevention of mother-to-child transmission (pMTCT) programmes in the UK and Ireland, paediatric HIV clinics are still seeing increasing numbers of infected children [1]. Most were born before universal antenatal screening for HIV (initiated in 1999) or are born to the decreasing numbers of women not identified as infected in pregnancy [2–4], that is, they have not been offered testing, have refused testing or were unbooked deliveries. Additionally, data show increasing numbers of children (from 20% in 1994/1995 to 60% in 2000/2002) with HIV who have been born outside the UK, in countries where universal screening and antiretroviral therapies are not available [1]. Consequently, HIV needs to be considered as a differential diagnosis in unwell children and in well children with maternal risk factors.

Children who are looked after away from home often have unmet health needs and can be at risk of a wide range of health problems, with only partial information regarding maternal and paternal health available. Due to this vulnerability, it is a statutory requirement that all looked-after children (LAC) undergo holistic assessments by a paediatrician [5,6]. Many have complex family histories with a higher incidence of sexual abuse and drug use, necessitating assessment of risk for blood-borne infections, including HIV [6]. HIV testing in children is difficult under any circumstance but it becomes even more challenging in children with complex family problems, necessitating social service involvement.

In two boroughs in north west London, a multidisciplinary working group was set up to write a joint health and social service guideline for the testing of LAC who are at risk of blood-borne infections. This article will outline the motivation behind the multidisciplinary working group and give an overview of the document in its current state.

Rationale for the guideline

From the perspective of the paediatric HIV team, we were keen to write a guideline because of a number of the referrals that were being made from social services and healthcare professionals. One of the most common problems we have encountered is HIV being identified as a disproportionate risk factor when hepatitis is actually more of a risk, for example, referrals for HIV testing in cases where

parents had a history of intravenous drug use (IVDU), when in fact prevalence of hepatitis B and C is much higher than HIV [7]. Concerns were also raised by many professionals about the difficulty of confidentiality in relation to HIV testing and status. Questions of who needs to be informed, in what circumstances and by whom, gave rise to debate and disagreement. There have been breaches of confidentiality, resulting from over-estimated concerns about the risk of HIV transmission, in part because of the lack of training and guidelines. Consequently, it became apparent that to normalise HIV, it should not be separated from other blood-borne infections and that agreed guidelines needed to be put in place.

Once this need was identified, a small multidisciplinary group met to discuss the issues. Initially, the group set about trying to identify an existing document. However, although guidelines were found for infected children and outlining the need for testing for blood-borne infections in LAC [8–12], no practical step-by-step guideline was found. Therefore, it was decided to put together a working party to write a guideline using published information from existing documents.

Aims of the guideline

The aims of the guideline were to provide:

- Multi-agency guidance to address the health needs of LAC who could be at risk of blood-borne infections.
- Information on hepatitis B, hepatitis C and HIV.
- Guidelines on consent and confidentiality.
- Procedures for how to identify, assess, test and refer children at risk of blood-borne infections.

Due to space constraints, an abbreviated version of the document is included here.

The guideline

Why test?

Because of the advances in the treatment of blood-borne infections, there are real advantages in determining the status of children who might have been exposed to the risk of infection.

It is recommended that all children up to 18 years of age who are put at risk of blood-borne infections should be tested. Children who have contracted blood-borne infections from their mothers can remain well for many years.

Without treatment and monitoring, all of these blood-borne infections can cause children to become severely ill and put them at risk of death. Information given on blood-borne infections and how they are transmitted is based on Department of Health (2005) *Children in Need and Blood-borne infections: HIV and Hepatitis* [9].

Obtaining consent

Informed consent is required before taking the blood tests. It is therefore essential that everybody working with a child being tested for blood-borne infections knows who has parental responsibility and whether the child has the capacity to consent because these are prerequisites to the power of consent.

As most children with blood-borne infections have acquired the infection from their mothers, identifying infection in a child is likely to indicate that the mother is also infected. Therefore, confirming infection in a child has implications for the whole family. The pretest discussion should ideally involve both parents and, when appropriate, the child or young person

- Consent for testing for blood-borne infections should be obtained by the paediatrician or specialist nurse testing the child. Verbal consent is adequate but should be documented in the notes.
- Further advice about tests for blood-borne infections can be obtained from local specialist teams.

Raising the concerns of a possible blood-borne infection with the parents and child when appropriate

This must *always* be done by a healthcare professional with appropriate experience. If any other professional has information that raises concerns, this must be passed on to the relevant healthcare professional.

Who can give consent for the child:

i. if the Local Authority shares parental responsibility (PR) with the parent.

In cases where the child does not have the capacity to consent themselves, the decision rests with those who have PR. When there is no argument with those with PR there are no difficulties. When there is an unresolved dispute between those who have PR the situation is more complicated, and legal advice should be sought straight away. Decisions made by those with PR or the court are to be made on the basis of what is in the best interests of the child.

ii. if the parents have sole responsibility

If the parents have PR and there are concerns about the child's risk factors for blood-borne infections but

the parents refuse testing, consult with the paediatric infectious diseases team. If the child is asymptomatic then there is time to work with families. In rare cases applications are made to court for the issue of consent to be resolved.

iii. in the case of young people over 16

Young people ages 16 or 17 can consent to their own medical treatment (Family Reform Act 1969). If a young person of 16 or 17 gives consent, it is not necessary to get consent from an adult with parental responsibility but it is good practice to involve the adult unless the young person does not want this. It seems from case law that the refusal of treatment can be overridden by a person with parental responsibility. However, in view of the lack of clarity in the case law and the rights of the young person, legal advice should be sought.

iv. in the case of children and young people under 16

A child or young person under 16 years old can give consent to treatment if they are 'Gillick competent' according to under the new Fraser guidelines. This means that a child who has sufficient understanding to understand fully the nature and implications of having tests for blood-borne infections will also have the capacity to give their own consent.

v. if the child is abandoned

In the case of an abandoned child there is an absence of persons with parental responsibility. Under the provision of the Children Act 1989, the local authority has the duty to safeguard the child's welfare and the power to do what is reasonable to safeguard the child's welfare. This would include consenting to test at the recommendation of medical practitioners.

Confidentiality and disclosure

- Information about the health or medical history of an individual is confidential to the person concerned and should be protected by local procedures.
- There are many circumstances when the provision of services does not rely on knowing whether the child has a blood-borne infection. However, sometimes knowledge of blood-borne infections is important for the child's medical or emotional well being.
- Before disclosing information about blood-borne infections to any agency or individual, the following points need to be taken into account in reaching a decision.
 - Is the disclosure in the best interests of the child and, if so, why?
 - What information needs to be disclosed and to whom?

- Do those with parental responsibility or the competent child consent to the disclosure?
- Are there risks to the carers/agency staff if the information is not disclosed?
- What are those risks?
- What is the ability of those informed to maintain confidentiality?

When to test children known to social services

The scenarios listed are common situations identified by the working group.

(a) Abandoned babies

All babies abandoned in the first 5 days of life, with limited or no information about their parents, are considered high risk and need to be seen urgently in the first 24 hours by a paediatrician. It is imperative that the baby is screened for all the tests the mothers would usually have in the antenatal period.

(b) Children whose parents are known intravenous drug users

All children who have a parent (either mother or father) who is an intravenous drug-user need to be tested for hepatitis C (HCV), hepatitis B (HBV) and HIV.

(c) Children about whom there are concerns over parental drug use and possible IVDU

All children need a comprehensive assessment by a paediatrician. Every child should be considered on an individual basis.

(d) Testing in sexual abuse and sexual exploitation

All children need a comprehensive assessment by a paediatrician with experience in the assessment of children who have been sexually abused.

(e) Children about whom information on one parent or both parents is incomplete and/or inadequate

As in section (c).

(f) Unbooked mothers (when mothers have no antenatal blood tests)

Infants or children of mothers who have not had their antenatal blood tests, or who are unaware of their results, will need screening for all the tests their mothers would usually have (rubella, syphilis, HIV, HCV and HBV).

(g) Children born to mothers with continuing risk of acquiring blood-borne infections in pregnancy

Antenatal blood tests are done at 12–18 weeks.

Therefore, if there are concerns about mother being at continued risk throughout pregnancy, testing children should be considered.

(h) Unaccompanied LAC from abroad

As in section (c).

(i) Foster carers with a blood-borne infection

- There is negligible risk to children cared for in homes of carers with HBV, HCV and HIV.
- HIV and HCV are not transmissible by living in the same house.
- There are reports of transmission of HBV between people living in the same house but they are rare and are associated with highly infectious status. Transmission can be prevented by vaccinating children cared for by HBV-infected foster carers.
- All foster carers should be given education on universal precautions.

(j) Foster carer caring for children with blood-borne infections

- All foster carers should be given training on universal precautions.
- It is more important for foster carers to know a child's diagnosis when a child is in a long-term foster placement and is significantly immunocompromised and therefore at risk of infection or on medication.
- If a child's status is unknown or they are uninfected but their parent has a blood-borne infection, the local authority must consider disclosure to third parties.
- If a child with a blood-borne infection is placed with a foster carer who is informed of the child's healthcare needs, extra information on blood-borne infections, transmission and social and medical considerations should be given. This should include contact details for healthcare professionals and details about any medication the child is taking.
- Foster parents of LAC with blood-borne infections need to be informed that the child's diagnosis is to be treated with the strictest confidence.

(k) Adoption

- All prospective parents receive counselling about HIV, HBV and HCV as part of their preparation process.
- If a child being placed for adoption is known to be HIV positive or to have HBV or HCV, the adoptive parents need to be informed.
- If a member of the child's family has HIV, HBV and HCV but the child does not, the test for deciding whether to disclose is used.
- When there are no risk factors for HIV, HBV and HCV, testing should not be carried out routinely before adoption or at the request of the adoptive parents.

Practicalities for testing children with blood-borne infections

Testing for blood-borne infections should be carried out according to local arrangements.

Conclusion

As stated earlier, this document is shortened for the purposes of this article, and is still a work in progress. However, it is very important to highlight the complexities of testing children for HIV and other blood-borne infections. Large numbers of children are tested for HIV and although many of these children are ultimately not infected, it is imperative that stigmatisation and fear surrounding HIV are not perpetuated in the testing process. Hopefully, not only the dissemination of the guideline and the associated training, but also the process of meeting to write it, will help to reduce stigmatisation experienced by families that are affected by HIV in the local area.

Once the document is finalised at a local level, the group plan to present the document to the Children's HIV Association for national use. However, if anyone is interested in seeing a copy earlier, or has any comments or advice, please contact me at the email address given below.

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Children's HIV National Networks

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This article will discuss the development of national networks of care for children with HIV in the UK and will refer to the Children's HIV National Network (CHINN) review [1].

Background

Children with HIV

There are now over 1000 children living with HIV in the United Kingdom [2]. Most acquired the virus from their mothers by vertical transmission during pregnancy, at delivery or through breastfeeding. There have been enormous advances in the care of children with HIV over the past 10 years and children are living much longer because of the use of antiretroviral therapy (ART). HIV is now seen as a chronic illness requiring long-term care and management. The increasing numbers of children with HIV now entering adolescence have led to the development of adolescent and transitional services in many centres.

Perinatal HIV

There have been huge improvements in the testing and care of pregnant women. In 1998, an intercollegiate working party recommended that all pregnant women in the UK should be offered and recommended an HIV test as part of their routine antenatal care [3]. This was implemented nationally from 1999 and, although women can refuse a test, the uptake has been high. Once it is known that a pregnant woman has HIV, there is the opportunity to reduce the risk of transmitting the virus to her infant. This is achieved by the mother going on ART, a caesarean delivery, the infant receiving ART for one month and avoiding breast feeding. If these interventions are made, the risk of transmitting HIV to the infant is approximately 1%.

The prevalence of HIV in pregnant women is increasing but it varies across the country, with some centres seeing 50 women per year and others seeing women with HIV occasionally [4]. Comprehensive national guidelines on the management of HIV in pregnancy and the prevention of infant transmission are available from the British HIV Association [5]. There should be a multidisciplinary approach to managing the care of these women and their infants.

Historical perspective

Paediatric HIV in the UK has historically been a London issue, with the majority of the children concerned living in or around the London area. This

led to paediatric HIV services being developed at Great Ormond Street Hospital, St Mary's Hospital and St George's Hospital in London. Most children with HIV were referred to one of these three specialist paediatric infectious diseases units. All of these units developed family clinics where children with the virus and their HIV-positive parents can be seen together. These clinics are multidisciplinary and involve paediatric infectious disease consultants, adult HIV physicians, paediatric and adult nurse specialists, health advisers, psychologists, dieticians and pharmacists.

Current picture

There has been an increase in the number of families with HIV being seen across the rest of the UK and now over half of all pregnant women with HIV and more than one-third of children with HIV are living outside London. As this shift continues, services have had to adapt. Services need to be family centred because a child with HIV usually has a mother with HIV. It is vital that these children and families have access to the same standard of specialist care wherever they live in the UK.

The majority (approximately 80%) of children with HIV and babies born to mothers with HIV in the UK are of sub-Saharan African origin and a significant number are asylum seekers. Two of the most stigmatised groups in today's society are immigrants and people with HIV, and the ongoing stigma surrounding HIV often prevents families with HIV obtaining the support they need. This is amplified in areas where they might not have appropriate support services because of the low prevalence of HIV.

Approximately 80% of children with HIV are on ART and there are more than 20 drugs available, with more being introduced each year. The management of adherence and the monitoring of side effects, toxicities, drug resistance and drug levels are becoming ever more specialised. This, with the complex issues of disclosure, of diagnosis and many cultural factors, makes paediatric HIV care very challenging. Detailed European guidelines on the management of ART are now available from the Paediatric European Network for the Treatment of AIDS (PENTA) [6]. The children's HIV association (CHIVA) has developed its own guidelines on other aspects of clinical and social care, which are available online [7].

Children's HIV National Network review

During 2002 and 2003, the London HIV consortium paediatric subgroup undertook a review of the services for children with HIV living in London. Their report, *Developing Clinical Networks for Paediatric HIV Treatment and Care in London*, gave formal recognition to three lead units for paediatric HIV care mentioned above [8]. These units now lead recognised clinical service networks in north east, north west and south London. Each network has lead clinicians, shared care protocols and guidelines.

Why networks?

Networks are complicated partnerships of all organisations and professionals that are involved in commissioning, planning and providing services for a particular speciality. They usually include a lead physician, lead nurse and network manager. The Calman-Hine report has led to the development of clinically managed cancer services throughout the country [9]. These networks cover the commissioning and delivery of all cancer services within a certain area. The aim was to ensure that the treatment and care patients receive is of a uniformly high standard.

The CHINN review originated from a national meeting of specialised services commissioners in October 2003. It was agreed that a review of current service provision would be undertaken and a report made on adopting a network approach. The aim of the review was to examine the current medical service provision for children with HIV living outside London and to make recommendations on appropriate models of service provision.

The Department of Health's Sexual Health and HIV division funded the review. A small steering group was formed, including representatives from Department of Health, CHIVA, the Royal College of Paediatrics and Child Health, HIV commissioners and the National Children's Bureau and the voluntary sector, including representation from outside London. A detailed, semi-structured questionnaire was developed, which included questions on the care of infants born to women with HIV, care of children with HIV, commissioning and structure of care and current network arrangements. This was distributed in spring 2004 to all paediatricians in the UK who had reported a child with HIV to the National Study of HIV in Pregnancy and Childhood (NSHPC) in the previous 5 years (Panel 1).

Discussion

The number of children with HIV living outside London is increasing. This is due to the rising global epidemic, recent patterns of migration and the dispersal of asylum-seeking families. There are currently no tertiary paediatric HIV centres outside

Panel 1: Results of the CHINN Review

Questionnaires were sent to 73 paediatricians at 63 centres outside London. Overall, 55 centres replied (an 87% response rate).

Perinatal care

Centres reported between 0 and 18 HIV-infected women delivering during 2003. Over 80% of paediatricians had already sought specialist advice on complex cases, with 59% holding a regular multidisciplinary forum to discuss the management of pregnant women and their babies.

Paediatric care

The numbers of children with HIV at each centre ranged from one to 37, with a total of 299 children under care identified outside London. Sixteen of 40 of centres (40%) were running a designated paediatric HIV clinic and seven centres (18%) were running family clinics. There were very few funded family HIV posts and many of the centres were struggling with increasing numbers of children and babies and a lack of staffing and resources. Nearly 80% of centres already had an informal shared-care arrangement with other hospitals, usually one of the London centres. Within regions, some units already had established links with main centres such as Birmingham.

London but a paediatric HIV specialist should be involved in the care of all children with HIV, either directly or as part of a clinical network.

Following wide consultation with stakeholders and regional workshops, this review has led to the development of a regional network structure for paediatric and perinatal HIV. This structure takes into account informal networks that were already in place and includes developing lead centres in:

- north-east England
- north-west England and north Wales
- the midlands
- south-west England and south Wales
- Scotland
- Northern Ireland

There are many centres near London that have established links with one of the centres in the capital and they will remain as direct London-linked centres.

There has been a lag between the increasing number of children with HIV outside London and the commissioning of services. Developing national networks with joint clinical governance and organisational development is essential in order to ensure families receive a high standard of care wherever they are in the UK.

Implementation

A CHINN implementation group was set up to oversee the progress of the regional networks. This is led by CHIVA and includes the lead paediatricians and nurses from all the networks, as well as commissioners and Department of Health representatives. The networks are in an interim

transition year from April 2005 with the expectation that CHINNs will be functioning from April 2006. It is envisaged that the lead paediatrician of each network will complete a progress report every 6 months.

Each CHINN now consists of a lead paediatrician and a clinical nurse specialist. These networks operate differently depending on their resources, practicalities and the needs of their patient population. Some centres offer a multi-disciplinary team approach including pharmacy, psychology, dietetic, allied health professionals and social work support.

Each region retains a link with one of the three tertiary paediatric centres in London. Each network will develop formal clinical governance including network meetings, training, collaborative audit and research. This arrangement enables the sharing of knowledge and training of clinical staff. Over time, it is intended that the networks will operate more autonomously while ensuring equity of service across the country.

How do the networks work in practice?

The CHINN linked to St George's Hospital, South Thames and Regions Children's HIV Network (STARCHIN) now includes networks in the north-east covering Sheffield, Newcastle and Leeds; the midlands, including Birmingham and Leicester, and the south west, including Bristol, southern England and south Wales. Each of these regional networks has a lead paediatrician, or two where appropriate, and a lead nurse. Each network holds regular multidisciplinary network meetings looking at staffing, commissioning issues, care structures and clinical governance issues.

The STARCHIN network now oversees the care of over 400 children with HIV. The lead paediatrician and nurse consultant from St George's Hospital visit the regional CHINN centres twice a year to meet the teams caring for the children. The meetings involve discussion on the care of the children with HIV; anti-retroviral management; perinatal care and structure of care and commissioning issues. Between meetings, the lead paediatrician or nurse contacts St George's for advice on more complex issues, such as antiretrovirals, disease management and difficult ethical or legal issues. There is also the opportunity for teleconferences for interim discussions. Staff from the regional centres can come to St George's to attend clinics or meetings for training or updates. St George's holds two multidisciplinary network days a year; these involve updates, training and discussions.

Conclusion

The CHINN review highlights many of the issues that are common to rapidly expanding, low number but highly complex subspecialty services.

The most effective way to care for children with HIV and infants born to women with HIV is within a clinically managed service network. The principle of care must be that all children with HIV and infants born to mothers with HIV have access to the same standard of care wherever they live in the UK. The CHINN review has helped to develop a more formal structure for some of the arrangements that were already in place.

CHINN Steering Committee

Mike Sharland	Chair of CHINN
Sheila Donaghy	Project Manager
Kay Orton	Sexual Health and Substance Misuse Division, Department of Health
Linda Johnson-Laird	Sexual Health and Substance Misuse Division, Department of Health
Sarah Jones	Assistant Associate Director North Central Specialist Commissioning Team
Gareth Tudor-Williams	Chair of CHIVA
Andrew Riordan	Alder Hey Children's Hospital, Liverpool
Nadeem Shafi	Birmingham Primary Care Trust
Magda Conway	National Children's Bureau
John Sweeney	British Association of Sexual Health and HIV

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Nursing support for HIV-positive families at Sheffield Children's Hospital

Jackie Hobbs

Clinical Nurse Specialist, Sheffield Children's Hospital

There has been a specialist HIV nursing service at Sheffield Children's NHS Trust (SCH) for over 6 years. During this time, the number of infected children reviewed, both in clinic and in the home, has tripled. Although these figures are still small, especially in relation to the larger London specialist centres, the increase demonstrates the need for an HIV centre in the north of England, especially with the dispersion of asylum seekers to northern areas of the country.

Our service at SCH is headed by a consultant paediatrician with a specialist interest in immunology and infectious diseases, who also manages the care of children with tuberculosis and allergies. The service is fortunate enough to also have a part-time specialist HIV pharmacist who attends clinics to offer advice and support along with the doctor and nurse.

The specialist nurse role includes the care of children with HIV primary immune deficiencies and allergies. Time is divided equally, when possible, between the three specialist areas. This is often difficult when home visits are required because travel between the hospital and home around South Yorkshire can be time consuming. If possible, visits are arranged for school holidays but for families of newly diagnosed children and those starting treatment, they are arranged for after school as this proves less disruptive to the child and family.

Responsibility for the completion of surveillance forms is also included within the specialist nurse role and, although it is time consuming, this can offer an opportunity to review patient notes carefully and highlight any issues that might have been overlooked or need to be addressed. This is not always possible on a regular day-to-day basis because time is often spent reacting to current and ongoing issues.

As there are few paediatric specialist nurses working in the north, support and advice is obtained from the London network of nurses. This provides discussion on various issues of case management and acts as an opportunity for clinical supervision.

This post, although difficult at times, is rewarding and constantly developing. There is space for further development but current staffing issues and low patient numbers do not make this a feasible option at the moment. Further development possibilities, for

example working with the team from Leeds, are discussed below.

Recently, the opportunity has arisen to be involved in the KwaZulu-Natal (KZN) rolling HIV programme, which is provided with support through the Children's HIV Association (CHIVA) and the University of KZN. This has provided an excellent learning and development opportunity and has been a rewarding project to be involved in.

Two HIV clinics are held monthly, one at SCH and the other at a local adult hospital, where a family clinic is held (Figure 1). This gives children and parents an opportunity to see both paediatrician and adult physician within one clinic setting. Parents find this an ideal opportunity to chat to each other and, where possible, children of similar age groups are put together in the same clinic so they can develop relationships while playing in the waiting area. Shared care with local district general hospitals (DGHs) is also an important aspect of care.

The family clinic at the local adult hospital provides an excellent opportunity to address transitional issues for adolescents, as both the paediatric and adult teams are available within one space. However, transition for those seen at the children's hospital to GU medicine at DGHs is a little more difficult to arrange between hospitals and often other towns.

Children attending clinics are assessed for their eligibility to commence clinical trials through

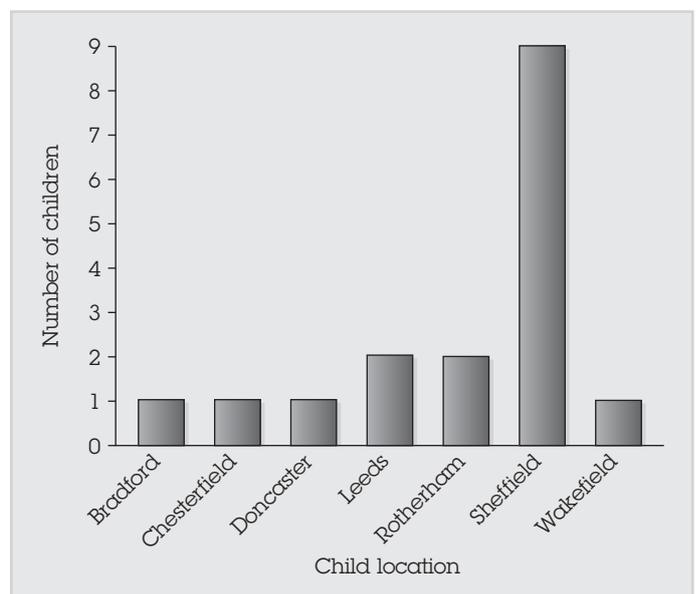


Figure 1: Children with nursing support from SCH

Paediatric European Network for the Treatment of AIDS (PENTA). There have been two children enrolled on to their PENPACT1 trial and three children previously on the PENTA5 trial.

Because many children will be under the care of more than one medical team or agency, parents often become confused as to who they should contact for advice on a particular area of their care. Acting as a key support person, advising or directing calls appropriately, takes some of the stress out of dealing with the child's condition for the family.

Alongside the medical input, there is support available from the adult social services team, which is based in Sheffield and is specifically intended for adults and families affected with HIV. They have a specific social worker working with asylum seekers, which has proven to be very beneficial because of the growing number of African families moving into Sheffield and its surrounding areas who require support and advice regarding accessing services. Psychology input is obtained on an as-needed basis through SCH psychologists, although advice is also available from the specialist adult HIV psychologist at the local adult hospital. Psychologists do not attend the clinics at either hospital. The same theory applies for dietetic services. Although there are paediatric dieticians available at SCH, none is specialised in HIV. Access to a specialist HIV dietician is available at the family clinic at the local adult hospital.

Sheffield has a local HIV support group that is easily accessible and holds regular meetings for infected women with children. They are currently working together with the Centre for HIV and Sexual Health in Sheffield to form an adolescent support group for those who are aware of their status. Both families and staff are very much looking forward to this, as it will offer an opportunity for adolescents to get together outside the hospital environment to make friends, chat and participate in social activities. For the time being, children are offered the support of 'Teen Spirit' at Body and Soul, an HIV support group in London, where some of them have pen-pal correspondence with people of a similar age and have found it useful. The adolescents are also invited to make contact with someone of a similar age who attends the clinic in Sheffield if they wish to have face-to-face support. This has also proved beneficial on a number of occasions.

The HIV services offered by SCH can be divided into three main groups: the support of local children and families infected with and affected by HIV in the clinic, via telephone and at home; shared care with DGHs; and the follow-up of children born to HIV-positive mothers.

Support of local infected and affected children and families.

Children are generally seen every 2 months in the clinic, although allowances are made for children

who are unwell, newly infected or have recently commenced treatment. All, when required, are offered home visits for further support and education.

Telephone support is offered between clinic and home, during which any issues from a particular visit can be followed up.

Regular home visits and contact is made with children before commencing treatment and after it has started. This ensures that families are adequately prepared for commencing their treatment and feel supported through the difficult period at the beginning of therapy. Because numbers of infected children in South Yorkshire are relatively small, this level of input is possible but might not be if numbers were larger.

Disclosure to infected children and adolescents and supporting families wishing to tell siblings or other household members about an HIV diagnosis, are areas where nursing support is vital. Home visits enable the nurse to build up a trusting relationship with the child and give the nurse the opportunity to educate the child gradually on aspects of their infection and to spend time with parents advising how full disclosure can be approached. After this time, the support network is in place for the child to express thoughts and feelings about their disclosure. Visits are planned at this time, as needed by the child or family; these often take the child out of the home environment so they feel more comfortable talking and expressing their true feelings, without feeling that they will upset parents or siblings. Adolescents can also feel more comfortable talking about sexual health or relationship issues outside the home, where they can feel that parents will interfere or disapprove. This gives an ideal opportunity for the nurse to offer health promotion and advice.

Shared care with DGHs

Ensuring that good communication between the shared care centres is vital for the continuation of care. Families can continue to contact the specialist centre for advice or support if the child is unwell but having access to a well-informed team at the local hospital in an emergency is important. When confidentiality is an issue for families, accessing health services out of their local town has its benefits, as they feel secure that their secret is safe. Encouragement and reassurance that local hospital staff will also keep their medical information confidential must be provided and no information should be divulged without the patient's and/or the parents' consent. In circumstances in which permission is not given to disclose information to GPs or local hospitals, parents are advised that an emergency disclosure of status will be required to safeguard the best interests of the hospital staff caring for the child and to ensure the child receives the appropriate type of care.

There is currently a shared care policy for some patients in Leeds and Bradford. Both centres have a paediatrician with an interest in HIV but neither has specialist nurse input. In these circumstances, the children are reviewed at the SCH clinic, where specialist nursing support can be offered and arranged. Although this might not be required for all children accessing services in Leeds or Bradford, support is accessed in certain cases. This might be for disclosure purposes, children requiring tablet training or families requiring more support than can be offered within the local clinic setting. This is currently an informal arrangement but steps are being taken within the North East Region HIV National Network (NERCHINN) to formalise this and have specialist nursing support between Leeds and Sheffield. Once developed, this will provide stronger links between both families and staff within the area and will provide nursing staff with the opportunity to develop further knowledge, skills and expertise in the area.

Follow-up of babies born to HIV-positive mothers.

Over the past 5 years, numbers have increased from one baby born in 2001 to 13 in 2005 (Figure 2).

There is currently a good network between obstetric, midwifery, paediatrics, social work and adult ID/GU medicine within Sheffield and multi-disciplinary case meetings are held pre-delivery for every family to ensure all necessary arrangements are in place to reduce mother-to-child transmission. Generally, the mother will meet a paediatrician or a specialist nurse pre-delivery and before discharge from the hospital. Regular telephone contact and/or home visits are offered to support the family with the infant's medicines to ensure that any potential problems are detected early. This is carried out alongside the midwife and good communication between the

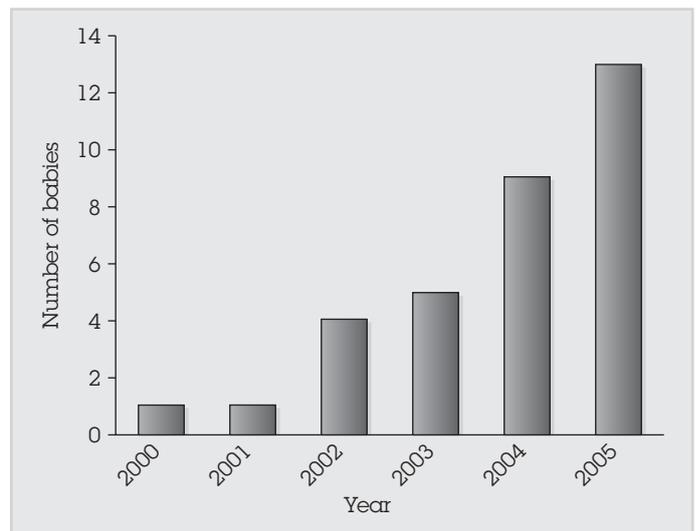


Figure 2: Numbers of babies born to HIV-positive women in Sheffield

disciplines is necessary to ensure there is no duplication of requested or given information, which can overwhelm the family. Babies are followed up either in the clinics or on the day-care ward, according to BHIVA guidelines.

Although the service provided by SCH for children and families with HIV is of a high standard and provides the necessary means of support, there remains much room for improvement. Staff continue to strive to find additional ways to provide further and improved service provision and to work closely with the adult hospital, DGHs and primary care teams to find support to set future plans in motion.

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Guidance for follow-up of adolescents with infancy-acquired HIV: an overview

Kim Gardiner

Clinical Nurse Specialist – Paediatric HIV, Waltham Forest Primary Care Trust

The document 'Guidance on transition and long term follow up of adolescents with HIV acquired in infancy', available on the Children's HIV Association website, encourages us to consider appropriate services for these young people as they begin the process of transition to adult services [1].

The National Service Framework document *Key Issues for Primary Care* states that 'all young people are to have access to age appropriate services,

which are responsive to their specific needs as they grow into adulthood' [2]. The guidance document acknowledges this, and points out that, although the needs for these young people will vary according to individual need, the core issues remain.

The guidance document also considers wider social influences with an impact on young people living with HIV and makes a number of recommendations. It also includes details of three models of care that are

used in transition for service providers to consider and apply as appropriate.

In summary, the guidance document contains the most detailed discussion of these issues currently available. It will be regularly updated.

Core issues concerning adolescents with infancy-acquired HIV.

Medical history. The effects of HIV on this group are largely unknown. They might include medium to long-term side effects of antiretroviral therapy and fertility problems.

Psychological issues. The normal psychological issues that accompany adolescence might be exacerbated by living with the psychosocial effects of HIV, including issues that surround disclosure of their status to others and dealing with aspects of developing sexuality. Young people taking long-term medication have the added burden of taking therapy and possible side effects.

Sexual development and sexual health. Acknowledging the difficulties in handling these issues with this group of young people, it is suggested that issues relating to sexuality might be better discussed with professionals from an appropriate adult team rather than existing contacts within the paediatric service. Routine sexual health screening needs to be encouraged early in this relationship. Little evidence has been produced on the effects of highly active antiretroviral therapy on sexual development or fertility.

Neurodevelopment and learning. Long-term multi-disciplinary follow-up is recommended for young people with severe cognitive deficits resulting from being immune-compromised, although currently there is little evidence to support this.

Social influences with an impact on young people living with HIV.

Individual These relate to any extra requirements for supporting the transition of a young person with severe disabilities or cognitive impairment. HIV is no different from any other long-term condition in this respect. Adolescents often have difficulties regarding adherence to treatment; often, the challenge for the health professional is to try to understand this from the young person's perspective.

Family For this group of young people, HIV is a family disease and, as part of this, roles such as being a young carer must be addressed. Other issues such as immigration and finance will also impact on a successful transition as these can take priority over health matters. Involving parents or carers in transition planning is key throughout the process.

Peers Young people carrying both an HIV and a non-HIV identity might experience conflict issues as

a result of a lack of understanding among their peer group. Opportunities must be made available to discuss and develop coping mechanisms and strategies in a supportive non-threatening environment.

School. Sharing a diagnosis, when appropriate, puts the young person's learning, behaviour or attendance into context and allows for appropriate monitoring. Once a young person reaches the stage of choosing a career, HIV brings about many other considerations and dilemmas.

Recommendations for follow-up of adolescents with infancy-acquired HIV.

- Where possible, arrangements for the transition to adult services of adolescents living with HIV should be evidence based.
- Adult services will need to change to respond to the needs of the lifelong chronic effects of HIV and its treatment on developing systems.
- Named practitioners from both paediatric and adult teams should assume responsibility for implementation and review of local transition policies.
- Larger paediatric centres should support smaller units.
- Young people should be represented in policy making and ongoing service review.
- Policies relating to transition should be developed in joint consultation with paediatric and adult services. They should take account of financial implications and satisfy clinical governance requirements of relevant service providers and commissioners.
- Priorities for central funding should include relevant research to provide comparative data and outcome measures to inform practice.
- Local funding should be incorporated within sector wide plans for HIV provision.
- A multi-agency forum should be developed for all involved professionals from voluntary and statutory organisations.

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■ *Conference 2006.* You should have received the 2nd announcement for the conference on 29th and 30th June in Leeds. We have a packed agenda for the meeting. We are glad to see that registration numbers are up on this time last year, but there is still plenty of time to get your application forms in. At the conference we will be asking for volunteers for the Executive Committee. If you cannot to attend the conference but are interested in joining NHIVNA or being more involved in our activities then please contact Nicky Perry via nhivna@mediscript.ltd.uk

■ *Study Days.* We have added four further study days this year. NHIVNA and Roche Pharmaceuticals are holding a meeting in Leeds, prior to the conference, on Wednesday 28th June. The theme is management of treatment-experienced patients. Talks include overviews of the challenges of treatment, resistance and barriers to treatment. All talks are supported by case histories for panel and audience discussions. Invitations will be sent to all NHIVNA members and if you are attending the conference then this will be a great way to start.

Future study days for the year include:

- 15 May 2006, 1000–1600. Topic: *HIV and co-infection.* Venue: London.
- 1 September 2006. Topic: *Metabolic issues in HIV.* Venue: to be confirmed.
- 20 October 2006. Topic: *HIV treatment review.* Venue: London.

■ *NHIVNA/Boehringer Ingelheim Grants and Scholarships.* This year we are pleased to include an additional category of scholarships. The Junior Nurse scholarship is open to any nurse with less than 2 years' experience of HIV nursing. Successful applicants will be funded to attend the NHIVNA conference. Applicants should submit a biography and justification of why they would like to attend the conference. Applications will be judged by the NHIVNA Executive Committee and winners will be notified of their fully funded conference place and support for travel of up to £50. The nurses do not need to be members of NHIVNA but it is hoped that they will join as a result of attending the conference. Eight places are available for this year's conference so if you know of any junior nurses who would like to apply please forward this information to them. Applications of not more than 500 words should be submitted to nhivna@mediscript.ltd.uk by 29th May and should be supported by the nurse's line manager.

We hope to see you in Leeds in June for the conference.

Nicky Perry, Chair, NHIVNA, Brighton

Book review

Patient-Centered Ethics and Communication at the End of Life

David Jeffrey

Radcliffe Publishing, Oxford, 2006,

ISBN: 1857756215, \$35

Reviewed by Lynn A Jansen

This book provides an introductory survey of the difficulties clinicians confront in providing quality end-of-life care to patients. The book is useful, well written and it makes a good attempt to cover the range of ethical and legal issues that routinely cause problems for clinicians who are trying to help their patients die a 'good' death. Despite the emphasis on ethical issues, Jeffrey is not interested in delving too deeply into theoretical reflection on ethics regarding the end of life. Instead, his main goal is to provide clinicians with practical advice on how to work through common ethical, legal and communication issues and the case-based format of the book is geared toward achieving this. The bullet-point highlighting of key points at the end of each chapter will make it easy for even the busiest of clinicians to read this book.

The author begins with a descriptive account of the nature and aims of palliative medicine, which he lucidly contrasts with the biomedical model of medicine. This section provides a helpful foundation for many of the issues discussed later in the book. Part two extends discussion of the palliative model of medicine by clarifying what is meant in palliative care by 'caring for the whole person' in the various stages of dying. Topics such as communicating bad news, obtaining informed consent, do-not-resuscitate orders, artificial hydration and nutrition and the limits of palliative chemotherapy are straightforwardly discussed in light of the goals and aims of palliative care. Of specific interest in this section is Jeffrey's (all too brief) discussion of the importance of introducing palliative care as a part of the treatment plan early in a patient's illness. He indicates that the failure to acknowledge and attend to the palliative care needs of a patient at the time of diagnosis can have

harmful ramifications for the patient and their family. Readers would benefit from a more detailed discussion of this matter. For example, what are the psychological factors that might prevent physicians from integrating palliative medicine early? Are there identifiable (and correctable) institutional and educational reasons why palliative care might not be widely applied in the care of the terminally ill?

The final part of the book addresses ethical aspects of physician education and the importance of multi-disciplinary teams in the delivery of effective patient-centred palliative care. The author concludes by drawing attention to the central role that the virtues and virtue ethics can have in guiding doctors who care for terminally ill patients. He recommends virtue ethics over other ethical theories because virtues 'are concerned with both actions and feelings' and 'virtue ethics provides insights into why decisions are difficult, justifies the need to accept advice and explains the existence of irresolvable dilemmas'. The implication of these statements is that other theories of ethics are deficient in one or both of these regards. This may be true, although I doubt it. However, because Jeffrey does not set out his arguments in support of these points, his preference for virtue ethics seems a mere assertion. Ethicists looking for a rigorous treatment of virtue ethics will not find Jeffrey's conclusions or style satisfying.

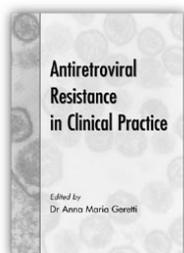
To be fair, the author admits that he did not set out to write a book on ethical theory. Nor did he intend to write for philosophers or trained ethicists. The book is addressed to practising clinicians, many of whom might be encountering the trials of end-of-life care and the ethical dilemmas associated with it for the first time. These clinicians will not only find the topics and information covered in the book to be practically useful, but will also find the straightforward voice of its author refreshing.

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(email: ljansen@svcmcnyc.org)

Antiretroviral Resistance in Clinical Practice

Edited by **Anna Maria Geretti**

Antiretroviral Resistance in Clinical Practice is a novel publication that has been developed to serve as a handbook for physicians dealing with the problems of antiretroviral resistance in their practice.



Antiretroviral Resistance in Clinical Practice covers an extensive range of topics (see below) written by eminent and internationally renowned authors led by the Editor **Dr Anna Maria Geretti**. Dr Geretti is a Consultant Medical Virologist and Honorary Senior Lecturer based at the Royal Free Hospital in London, and has a special interest in antiretroviral therapy and resistance.

The book examines the mechanisms of resistance to reverse transcriptase, protease and entry inhibitors with contributions from **Charles Boucher, Noortje van Maarseveen, Nicola Mackie, Anne-Geneviève Marcelin, Eva Poveda and Vincent Soriano**. With chapters by **Martin Däumer and Tobias Sing, Alessandro Cozzi-Lepri, Karin Metzner, Carlo-Federico Perno and Ada Bertoli, Caroline Sabin and Martin Schutten**, readers will be able to gain a valuable insight into the complex topic of resistance and obtain an update on the various methods used to measure, predict and interpret resistance.

Françoise Brun-Vézinet and Diane Descamps review the overall benefits of resistance testing, while **Andrea De Luca** examines the impact of resistance on viral fitness.

Marta Boffito investigates the pharmacokinetic implications of resistance, and **Ricardo Camacho** discusses the implications of HIV-1 subtypes on resistance testing, while **Clare Booth** gives an overview of transmitted resistance.

Finally, there is a chapter dedicated to a series of case studies, compiled by experienced clinicians, which are accompanied by an expert commentary.

Antiretroviral Resistance in Clinical Practice will prove to be a valuable handbook to all those who want to understand the increasingly complex problem of antiretroviral drug resistance in HIV medicine.

Topics covered in *Antiretroviral Resistance in Clinical Practice*:

- Mechanisms of resistance
- Transmitted resistance
- Evolution of resistance in treatment failure
- Minority resistant mutants
- The impact of resistance on virus fitness
- Benefits of resistance testing
- HIV-1 subtypes and resistance
- Resistance tests and their interpretation
- Statistical analyses of predictors of resistance

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