

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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A focus on children and adolescents

Sheila Donaghy

Guest Editor

Welcome to this summer's edition of *HIV Nursing*, which focuses on children and adolescents with HIV. Having worked in Paediatric HIV since 1995, like many of you, I have witnessed the huge developments in this field over that time. Initially, we were caring for mainly younger children, with high levels of morbidity and mortality. Drugs for children were just becoming available but initially we only had zidovudine monotherapy. The rate of HIV testing in pregnancy in the mid-1990s was relatively low and missed many of the pregnant women with HIV, and babies were still becoming infected. With the introduction of the routine offer, and recommendation, of HIV testing to all pregnant women coupled with effective prevention of mother-to-child transmission interventions, transmission is now less than 1% and has been a huge success story.

There are now more than 20 antiretroviral drugs that in combination can suppress viral replication and as a result both morbidity and mortality have been greatly reduced for children and adults with HIV. Just as many of us working in the field are getting older, so too is the cohort of children ageing. In 1996, just 11% of the cohort in the UK and Ireland was aged 10 years and over and by 2008 this proportion had risen to over 60%.

This is very hopeful but has brought with it new challenges, such as maintaining long-term adherence to medication, particularly during adolescence. Disclosure of diagnosis was often not a priority initially; however, the process of the child learning in stages about their illness is now started early on. We have had to become far more skilled at caring for adolescents and meeting their specific needs. We have learnt much from our adult colleagues about working with young people around sexual health issues. Many of the adolescents have complex needs with multi-drug resistant HIV, cognitive delay and psychosocial problems, and many have also experienced bereavements. This has led to the development of transition services and tailored youth clinics to meet their complex needs. A number of these young people are now supporting other young people with HIV. The articles in this edition explore many of these issues and we hope you enjoy reading them.

The first article is an excellent and comprehensive review of Paediatric HIV in the UK and Ireland by Michelle Goode CNS and Professor Karina Butler, who both have many years of experience in the field. They highlight the amazing success of the prevention of mother-to-child transmission

programmes. They look at the benefits antiretroviral drugs have brought but also at the challenges of maintaining long-term adherence to treatment. The authors explore the sensitive issue of disclosure of diagnosis, and how professionals can skilfully support the child and parents through this process. Michelle and Karina end by reminding us all to be aware of children who may need testing for HIV and to ensure that they do not miss out on the benefits of testing.

Susan McDonald then gives a wonderful and enlightening overview of adolescents with HIV and their transition to adult care. Adolescence can be a challenging time for young people in general but particularly for those with a chronic health condition. This is even more so when that condition is HIV, with the associated stigma and the need to deal with it as a sexually transmissible illness when forming relationships and becoming sexually active.

Susan highlights the importance of these young people being looked after by professionals who understand, and can meet, their particular needs. She explores the different transition models that have evolved. Some clinics run specific adolescent transition clinics jointly run by paediatric and adult services and some of the larger clinics are able to run separate young persons' clinics for HIV-positive adolescents. These can only be run in centres where there are sufficient numbers of young people with HIV but Susan points out that the most important thing is that the process of transition is planned and tailored to the young person's needs. This should be co-ordinated by a named worker and the young person should meet the adult team beforehand to ensure a smooth transfer. Good collaborative work between the paediatric and adult teams is essential and Susan demonstrates how services can remain young person-centred.

Cathryn Benson describes an interesting case of a 14-year-old boy with adherence difficulties. The study demonstrates a collaborative approach to supporting adherence and the use of directly observed therapy. Many adolescents struggle with adherence and this shows one approach to managing adherence to antiretroviral therapy. As it is relatively expensive, it can only be a short-term measure but can be valuable in establishing a good pattern of taking medication. It clearly helped this young person and his mother.

Alongside all the clinical improvements there was a need for information and guidelines for professionals and as Marthe Le Prevost *et al.* describe, in 2002 CHIVA (Children's HIV

Association) was formed. CHIVA is now the main professional association for those working with children and families with HIV. Marthe describes the work of CHIVA in writing clinical guidelines and standards of care for children and families with HIV. CHIVA was successful in obtaining a generous grant from the Elton John Foundation for a 3-year project. Marthe explains the three main aspects of this project: developing the website; running a summer camp for young people with HIV; and setting up a youth committee. The website project has many sections including the development of web-based resources for children and young people, their families and practitioners. There will also be a secure section on the website for young people with HIV and the formation of a Youth Committee so that young people have a voice. This

summer, CHIVA will run its first camp for 100 young people with HIV, which will be hugely beneficial for those attending.

As you can see, there have been many exciting developments in paediatric and adolescent HIV and we hope you will find these articles interesting and informative.

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A review of paediatric HIV in the UK and Ireland

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Introduction

Worldwide, 2.1 million of the estimated 33.4 million people living with HIV are children under 15 years of age and most live in sub-Saharan Africa [1]. In contrast, data from the Collaborative HIV Paediatric Study (CHIPS) Report to the end of March 2009 confirm a total number of 1161 HIV-positive children currently alive and in active follow-up in paediatric HIV services in the UK and Ireland [2]. These low overall numbers are primarily the result of well-structured and coordinated prevention of mother-to-child transmission (PMTCT) programmes. The programmes involve high uptake of antenatal testing, antiretroviral therapy (ART) for women in pregnancy, prophylaxis for the infant and the avoidance of breastfeeding [3]. The result is a low HIV transmission rate of <2% to infants [4]. Whilst the success of the PMTCT programme is clear, it is dependent on the financial support of national governments and is a picture seen largely, but not exclusively, in resource-rich countries. Prevention initiatives supported by governments in some developing countries have also produced favourable results. These include: the use of ART for the pregnant mother and exclusive breastfeeding with simultaneous maternal or infant ART for the duration of feeding [5]. The World Health Organization (WHO) has revised its recommendations for HIV and infant feeding in resource-poor countries to reflect these initiatives but continues to strongly recommend formula feeding where it is safe to do so [6].

Care of children and adolescents

HIV diagnosis

Of the total number of children with HIV infection in active follow-up in the UK and Ireland, 78% are of black African ethnicity, 7% are white and 51% are female [2]; 50% of the total number were born abroad and, of these, the median age at presentation is now over 9 years [2]. It is likely that a number of these children had been in the UK/Ireland for some time and opportunities for earlier diagnosis were missed [7]. Whilst some studies suggest that a small number of young people (at least 10%) with vertically acquired HIV survive childhood without ART and are asymptomatic at diagnosis, others are severely compromised and present with impaired growth, encephalopathy and opportunistic infections [8]. Clearly, early diagnosis is the key to preventing

progression to AIDS and increased awareness among all healthcare workers with greater use of HIV testing is required to reduce delays.

Of HIV-infected children born in the UK and Ireland, the median age at presentation is 6 months [2]. These infants fall into two groups. The first group includes those infants who become infected despite maternal diagnosis antenatally and referral to a PMTCT programme. In general, these infants become infected because of persistent maternal viraemia; either because of maternal non-adherence or very late presentation and initiation of therapy. More rarely these infants may represent early *in utero* transmission where infection has already occurred prior to initiation of maternal treatment. The second group of infants are those whose mothers have either not been tested in pregnancy or those whose mothers seroconvert in pregnancy or the early *post partum* period after a negative antenatal HIV screening result. These infants will miss the benefit of prevention strategies and infant diagnosis is often delayed, prompted by development of symptomatic disease or maternal diagnosis. Introduction of point-of-care testing in delivery wards could have a role in reducing this. Very encouragingly, the transmission rate to infants from mothers who receive HAART in pregnancy and who are fully suppressed is now 0.1% [4].

The approach to HIV testing is age dependent. For children over 18 months of age, diagnosis is made by detection of HIV antibodies in serum. Children under 18 months of age, born to HIV-positive women will test positive for HIV antibodies, the result of passive transfer of maternal antibodies *in utero*. Definitive diagnosis in this group requires the use of PCR tests to detect viral RNA or DNA [9]. Testing should be offered to all infants of mothers with HIV infection, to children born in endemic countries and to children presenting with recurrent infection or symptoms consistent with HIV infection. However, the future for HIV testing lies in the acceptance of it as a routine test for children outside the paediatric infectious disease arena, with a positive result prompting referral to a specialist service.

Treatment and treatment adherence

HAART, which was introduced in mid-1997, has been tremendously successful [10]. The proportion of HIV-infected children aged 10 years and over has increased from 11% in 1996 to 61% in 2008,

reflecting that success [2]. Optimism has been tempered, however, by a growing understanding of the challenge of maintaining long-term adherence to treatment. The CHIPS data show that HIV suppression in treatment-naïve children starting ART has improved from 45% between 1997 and 1999 to 75% for 2006 onwards [2]. Whilst these numbers demonstrate an improvement over time, studies indicate that sustained viral suppression of HIV requires a 95% or greater adherence to treatment [11]. A number of impediments to successful adherence have been identified in paediatric HIV literature. These include: high pill burden; foul-tasting medications; child refusal; side effects; multiple HIV infections in the same family; and changing family dynamics relating to parental illness [12]. The addition of developmental constraints of childhood makes treatment adherence a greater challenge for this group. CHIVA has published helpful guidelines to enhance adherence in this population and advocate the involvement of the multidisciplinary team in planning and maintaining children on treatment [13]. Among the pre-treatment planning strategies recommended are: examination of the family's readiness for treatment; assessment of who will take responsibility for giving medication to the child; assessment of the child's understanding of their diagnosis and of their need for treatment; and, importantly, supporting the child's and the family's active participation in treatment decisions.

Establishing adherence, particularly in the first month of treatment, requires that problems, such as taste aversion and side effects, are resolved quickly and taking medicine becomes a part of the family's daily routine [13]. However, maintaining adherence in practice is difficult, especially for young people, many of whom are reaching adolescence with multiple antiretroviral drug exposures, poor adherence histories and, consequently, multiple resistance mutations. This in turn results in the need for more complex ART regimens and an increase in disease-related morbidities [14]. Close contact with, and within, the multidisciplinary team is required to support the family and young person.

Disclosure

There is a growing body of data acknowledging children's autonomy and the importance of their role in decisions relating to their own care [15]. Certainly, in order for children and adolescents to be involved in healthcare decisions, they should be involved in truthful, age-appropriate discussions about their diagnosis. This fundamental issue of disclosure is one of the most controversial topics of discussion in paediatric HIV literature. Many working in the area of paediatrics believe that sharing information with children at an appropriate developmental level is best practice, but parents often delay this process [16]. Their concerns are well

documented and include fear of upsetting the child, fear of difficult questions that might be asked, simultaneous disclosure of parental HIV infection, and the fear that their child will tell others with the subsequent potential for discrimination and stigmatisation [17].

The general consensus of professionals working in paediatric HIV is that disclosure should be a gradual process taking into account the child's developmental stage, clinical status and psychosocial circumstances. The importance of supporting parents throughout the disclosure process is uncontested. Where parents are reluctant to disclose, be mindful of, and sensitive to, their challenges and move forward slowly with the guidance of the multidisciplinary team and guidelines produced by CHIVA [18]. This is important in order to avoid irreparable damage in parent-child-professional relationships.

What is clear is that there comes a time where the parent's right to refuse to disclose a diagnosis of HIV to their child may be subsumed by the child's right to know. This is particularly an issue in adolescence where young people are developing sexual relationships with peers. Whilst fear of transmitting disease has been demonstrated to impact on their ability to develop close personal relationships, most paediatric HIV services have experience of pregnancies in perinatally infected adolescent girls [19]. A recent audit of pregnancies in women growing up with HIV acquired perinatally or in early childhood confirms 36 pregnancies in 27 of 172 women in follow-up in the UK and Ireland [20]. Clearly then, the risk-taking behaviours of this group do not differ from those of non-infected adolescents. However, the implications of being sexually active have far-reaching consequences in the context of HIV infection. This behaviour, as well as placing themselves at risk of contracting sexually transmitted infections, places unsuspecting partners at high risk for acquiring HIV infection.

The age of, and capacity to, consent to sexual intercourse must also be considered. In the UK, the principle of Gillick Competence of young people between the ages of 13 and 16 is used to assess capacity to consent [21]. In Ireland, a person under 15 years of age cannot legally consent to any sexual act, while a person under 17 years of age cannot legally consent to sexual intercourse. It is not accepted as a defence to allege that the victim consented [22]. Gillick Competence has not yet been tested in Irish Courts; however, the Irish Medical Council believes that the courts may move towards a position whereby it is accepted that some form of assessment of patient's capacity to consent is required [23]. HYPNet have produced draft guidelines to help professionals working in the UK with this unique group of young people. A risk assessment for child sexual abuse and/or coercion is recommended as an integral part of history-

taking from anyone over the age of 18 who is sexually active [24]. The guidelines can also be applied in the Irish setting, with attention to the different legal constraints. Doubtless, young people with HIV find disclosure of sexual activity to healthcare workers extremely difficult. It is therefore incumbent on us to address the issue with sensitivity and discretion. It is important to assure them that subsequent disclosures to authorities are necessary only where an issue of harm or child protection is suspected. In addition, healthcare workers should inform adolescents of their legal responsibilities to protect sexual partners from HIV infection and document that this has been addressed in the medical file. Sexually transmitted infection screening should be offered to all sexually active adolescents.

Transition to adult services

Finally, transition to adult services for adolescents living with HIV has been an issue of tremendous interest and importance. It is a relatively recent but welcome challenge since the introduction of HAART. It is important to distinguish the term 'transition' from 'transfer'. Transfer is a term used to describe an event involving the movement from one healthcare service to another, this being just one component of transition [18]. CHIPS reports a total number of 204 adolescents who have transferred care to adult services up to the end of March 2009 [2]. Initial data on adolescents with HIV infection who have transferred suggest poor attendance at outpatient clinics and poor adherence to medication when compared with younger children and adults with HIV [14]. Transition, on the other hand, is a gradual and complex process of emotional, psychological and physical preparation of the adolescent and family for the move to adult care. Appropriate management of this transition is essential and guidance is provided by CHIVA in this respect [18]. Preparation of the adolescent for transition can only be started when the young person has been involved in a full and open discussion about their diagnosis. Thereafter, knowledge of HIV, HIV transmission and treatment should be regularly assessed and will change over time as they grow and mature. In addition, the adolescent should be given time in clinic without a parent/guardian present to facilitate their growing independence. The movement to adult services should be a concept that is introduced gradually, with partnerships developed with the adult team over time. The support and input of the multidisciplinary team is as an essential component in assisting transition and the development of a transition care plan with the adolescent and their parents/guardians. The process of transition is essential if the effective transfer of adolescents to adult services is to take place.

This review has dealt primarily with children and adolescents who acquired HIV in childhood. Another important group is adolescents who acquire HIV in adolescence through risk behaviours such as sexual exposure or injecting drug use. Mental health issues are a particular concern for this group, discussion of which lies beyond the scope of this article. The complexities of care for sexually active or drug-using adolescents who may be homeless and suffer from depression require special consideration, and their needs are usually best met in a focused adolescent clinic.

Conclusion

The unique challenges of caring for children and adolescents with HIV infection are imbedded in the complex issues of adherence to medication, disclosure of a diagnosis and transition to adult services. This list is not exhaustive and each issue is inextricably linked to the psychological development and lived experiences of each child and family. The challenges for the paediatric multidisciplinary team are to change and grow commensurate with the child, to provide support to the family and to provide a physical and emotionally inviting environment where children and young people feel at ease to share their personal information. In addition, it is incumbent on us as healthcare workers, whatever our area of expertise, to be mindful of the need to offer children the benefits of HIV testing. It is important that the frequency of missed opportunities for earlier diagnosis is reduced. Missed opportunities result in delays to diagnosis and a compromised child and family.

Finally, antenatal diagnosis of HIV infection and the availability of potent and combined antiretroviral therapy to treat HIV have resulted in reduced transmission rates to infants born in the UK and Ireland. Early diagnosis and potent ART for children has increased long-term survival and many are expected to reach adulthood and transition to adult services. The challenges are great but not insurmountable and the input of the multidisciplinary team is crucial to their safe and successful transition from child to adolescent and eventually to adult.

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Transition: are we there yet?

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Background

Since the introduction of highly active antiretroviral treatment (HAART), HIV-positive children are now surviving into adolescence and adult life in the UK [1]. Hence, increasing numbers of adolescents are transitioning from paediatric to adult services. The Collaborative HIV Paediatric Study (CHIPS; www.chipscohort.ac.uk) collects data from participating centres and captures approximately 93% of children diagnosed with HIV in the UK. Data to the end of March 2009 show that out of 1560 children living with HIV in the UK, 212 have already transferred to adult services, at a median age of 17 years [2]. Experience with children living with other life-long, chronic health conditions, such as diabetes, congenital heart disease and cystic fibrosis transferring over to adult services is associated with increased rates of morbidity and mortality [3,4], primarily due to loss to follow-up. There is evidence from one study to suggest that meeting the adult team who will be involved in the young person's care, prior to transfer, increases subsequent engagement with services [5].

What is transition?

'a purposeful planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.' [6]

Adolescence itself is a time of transition between childhood and adulthood, a time of development with the focus on becoming more independent and free to make decisions. It is a time where there is a more heightened sense of self-identity and emotions. It is a phase in life to experiment, to push the boundaries and when the desire to be socially accepted by peers, to be the same as everybody else, is very strong. There are various ages to define adolescence. The WHO definition has adolescence ranging from the ages of 10 to 19, while in the UK 12–20 years is commonly accepted. There is no blanket rule of when the transition process should start and the age when transition culminates in transfer to adult services [7]. What is important is that it is individualised for each young person; this should be a guided educational and therapeutic process that is centred on the young person and it should consider the implications for the young person and their family. The National Service Framework (NSF) [8] has set out standards of care that aim to meet the holistic needs of young people, as Standard 4 demonstrates (Panel 1).

Adolescents are different from children and adults, and it is important to recognise that they need to be looked after by people who understand their particular needs and that they should have services designed specifically for them. The Department of Health recognises that health services do not meet the often complex needs of adolescents living with long-term health conditions, and that adult and paediatric services need to adapt in an effort to engage and support young people through the transition process [9]. The Department of Health has developed a range of transition guidelines and best practice [8–12], which can be used as a framework on which to base services.

Transition models

CHIVA (Panel 2) and the Department of Health [2,12], have developed transition models to use in practice, and their suitability depends on factors such as resources, paediatric and adult teams, and patient numbers. For example, at St Mary's Hospital, where there is a large cohort of HIV-positive children and adolescents, a combination of the family integration and youth clinic approach has been adopted (Figure 1). However, this would not be feasible for a smaller unit with fewer young people transitioning. What is important for each service, is that the model on which it is based provides a framework for care provision that meets the following standards, as set out in the NSF for Children, Young People and Maternity Services [4]:

- Health transition planning;
- Engaging the young person;
- Supporting the family;
- Young person-centred approach;
- Well-coordinated health plan;
- Continuity of care;
- Multi-agency setting;

Panel 1: Standard 4 of the NSF for Children, Young People and Maternity Services [8]

- Young people supported to make the transition to adulthood and to achieve their maximum potential in terms of education, health, development and wellbeing.
- Young people taking responsibility for their own health and making informed choices and decisions regarding their emotional and social development, and health and wellbeing both now and in the future.
- Services and staff who are able to respond in a sensitive way, which encourages engagement and provides high-quality support for young people.

- Confidentiality and information-sharing;
- Collaborative working/team approach;
- Knowledge, skills and responsibilities required by health professionals working with young people.

Health transition planning

This is a process that is recommended to start in childhood, by initiating discussions with parents/guardians on steps to prepare the young person for full disclosure of HIV. Before transition can begin, the young person needs to have an open discussion of their HIV diagnosis. Ideally, young people should be aware of their HIV diagnosis by 12/13 years of age, but this can vary depending on the family/guardians and the young people themselves [13]. Once the HIV diagnosis is known, the transition can begin. This involves age/cognitive ability, appropriate health education, information/discussions on relationships and sexual health and the opportunity to spend part of the clinic appointment with the healthcare provider on their own. Often, young people don't remember or fully understand the significance of health or social events during childhood and spending time reviewing their history can be helpful. This is a process that will take several years, until the young person is ready to transfer over to either a dedicated young person's HIV clinic or to

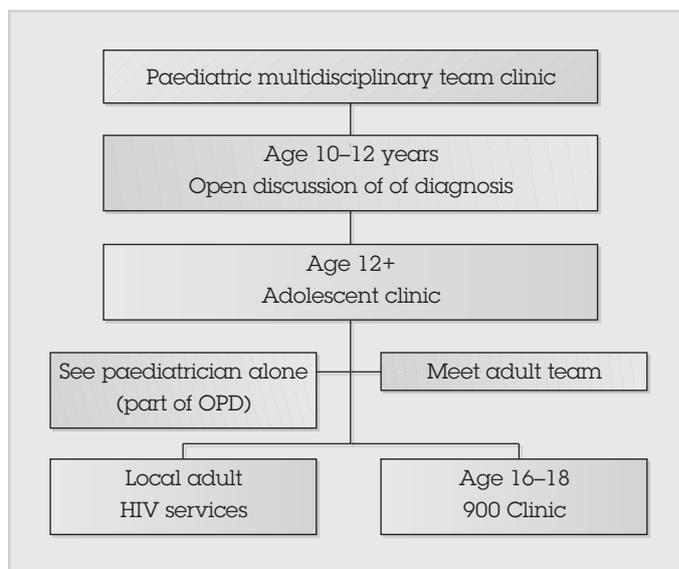


Figure 1: St Mary's Hospital model for the transition of care.

an adult service. Having a named healthcare professional (nurse, health advisor, doctor), that the young person is familiar with, to coordinate the transition, facilitate visits to adult services and introduce the young person and family to the new adult team, can help this be a more seamless transfer. This approach has been recommended in the RCN transition guidelines [14] and has been linked to better follow-up rates in adult services [3].

Panel 2: Models of transition

■ Model 1 *Family clinics: integration*

Where HIV-positive adolescents are cared for by HIV Family Clinics, the transition to adult care can occur in an integrated fashion. Special clinic times within the Family Clinic can be set where adult services are also present. The setting remains familiar but the young person begins to take responsibility for their own health, and visit or have consultations with the care teams on their own. The time period for this transition depends on each young person and his or her readiness to take on this new responsibility.

■ Model 2 *Specialist services: handing over*

Where a family or adolescent clinic does not exist, the transfer of care from paediatric to adult services is still possible with a carefully planned and comprehensive transition programme. This can only work when paediatric and adult services fully understand the transition process and work together productively.

■ Model 3 *Specialist services: separate youth clinic*

Creating a separate 'youth' clinic where young people can choose to go for their care offers a tailor-made specialist clinic that has solely HIV-positive adolescents attending and taking responsibility for their own sexual and medical health needs. This may also give young people the opportunity to interact with other HIV-positive young people and help shape the clinic to their own specific needs. However, it may not be suitable for younger adolescents and may also require a further transition into adult services at some future point.

Family approach

In most cases, young people who are transitioning from child services are living with a 'family disease' in which one or more parents is HIV positive and siblings are infected or affected. Bereavement and loss has impacted on family and social networks, and many young people don't have the support at home to manage health during this difficult time. Family dynamics can mean that adolescents are main carers and often take on the parental role. Social issues such as immigration and financial difficulties can take precedence over health management within the family. Involving the family during the transition process and helping them to support the young person is important. Some adolescents are under the care of social services, and so involving social workers/youth workers is also key to help support them through this difficult time.

Engaging the young person

HIV remains a stigmatised health condition so families tend to keep this information tight. In many circumstances, due to feelings such as guilt, family loss, fear of onward disclosure and keeping it a secret from other members of the family, HIV is not discussed in the home. This can be a barrier for the young person to discuss issues relating to living with HIV with family members or peers. Keeping HIV a secret can lead to difficult emotional feelings for

young people and uncertainty for the future [15]. Often for young people, the clinic is the only 'safe place' to have these conversations, but often it is not easy for them to approach health or social care providers about feelings or concerns. Building up a trusting relationship and giving young people the permission to have these discussions is really important. Working within a multidisciplinary team and offering a 'one-stop shop' approach to care can help to provide this support opportunistically. Having information on local peer support groups or one-to-one counselling and referral pathways in the clinic can provide young people with the right information and ease access to such services if they choose.

Building up a trusting relationship with adolescents can be very challenging, and efforts should be made in early adolescence to facilitate an environment where they have the opportunity to see a member of the team on their own. To build up a therapeutic trusting relationship can take time and thus, continuity of care is important to ensure that this can be a more natural process [16]. Making use of opportunities like getting weighed or phlebotomy (with appropriate privacy) can help the health provider to get to know the young person, which over time will help to build a trusting relationship. Being non-judgemental and open is essential.

Difficult issues need to be addressed during adolescence, such as relationships and sexual health. Negotiating first sexual relationships with a health condition that can be sexually transmitted can be an incredible burden to bear, and a sensitive, empathetic and understanding approach is needed. Sexual and reproductive health guidelines for this group are out for consultation and can be found online at the HIV in Young Persons Network (HYPNet; www.hypnet.org.uk). Getting to know young people as individuals and, over time, finding out what they want from the service is really important.

As healthcare providers, our main aim is to reduce morbidity and mortality. This usually involves the use of antiretroviral treatment. Adherence to antiretroviral treatment can be very challenging during this period. Psychosocial factors can contribute to poor adherence or patient-selected treatment interruptions but in reality, for many young people, past experiences and treatment exposure can result in combinations of drugs that have high pill burdens, side effects and more frequent dosing intervals that just do not fit into their hectic young lives. Sadly, a small number of young people opt not to take antiretroviral treatment, for reasons that are complex and difficult for the young person and their carers to understand. This is extremely challenging for the team and family/carers looking after these young people. Providing a service where the multidisciplinary

team can explore support options with the young person, which in some cases will involve palliative care interventions, is essential.

Young person-centred approach

How can we ensure that young people have a voice in the healthcare services that they want? The National Children's Bureau (www.ncb.org.uk) have organised weekends away for adolescents living with HIV, and hold small consultations to address this. CHIVA are working closely with HYPNET and the voluntary sector and have set up a youth group, to help young people have a voice (www.chiva.org.uk). Using questionnaires or holding small consultations with adolescents in clinic can be a good way of finding out what they think about their transition. It's good to be mindful that service providers may not be the most appropriate people to ask this, as young people may not feel comfortable about being honest with care providers. Volunteers or students (psychology/medical/nursing), looking for projects can be a good option. For example, in the 900 Clinic (young persons' HIV clinic) a medical student [17] designed questionnaires and led the project, aiming to find out what our young people thought about transition and their experiences. Interestingly, what was more important than the environment or peer support, was trusting relationships with care providers and respecting the need for independence and control (Table 1).

Confidentiality and information sharing

Young people have the right to a confidential service, and this includes the provision of relevant information, support, and healthcare in the absence of parents/guardians if this is their wish.

From the age of 16, young people have the legal right to consent to healthcare independently [18], unless there are any grounds for questioning capacity, in which case, guidance is available from the Mental Capacity Act [19]. For those under 16 years old, if they meet the Gillick competency ([20], Panel 3), they can access contraception and sexual health services independently, if this is seen to be in the best interests of the young person.

There is diversity in culture, ethnicity, social background and family network within our HIV adolescent cohort and some young people may have been in more vulnerable situations than others. Safeguarding is really important and it is good practice to inform young people prior to assessment that confidentiality may be broken and relevant information shared if there is any risk to the young person or others [21]. The age in years of a young person does not always indicate maturity or mental ability [22]. Finding a way to identify young people who are more vulnerable and provide

Table 1a & b: Views of young adults on their transition care [17]

(a)		
<i>All respondents found the following important</i>	<i>Percentage who found it strongly important</i>	
Staff explaining management comprehensively	81%	
Being understood and treated as an individual	81%	
Encouraged independence and control of care	76%	
Feeling comfortable about worries and health problems	71%	
Staff know how to talk and listen to young people	65%	
Pre-transition explanation	50%	
(b)		
<i>Some respondents found the following less important</i>	<i>Percentage who were neutral</i>	<i>Percentage who disagreed</i>
Sexual health information and condoms in the waiting room	43%	0%
Information on organisations for young people with HIV	38%	5%
Events or outings for young people with HIV	33%	10%
Meeting young people with HIV	48%	5%
Waiting room has new magazines and interests	48%	5%
Other young people in the waiting room	52%	24%

appropriate support can help bridge the gap between the law and safe practice.

Knowledge, skills and responsibilities required by health professionals working with young people

The Department of Health has developed standards for all staff that work with, or come into contact with, children, young people and their families, as outlined in standard 3 of the NSF [4]. One of the key skills required is confidence in discussing sexual health and relationships issues, substance and alcohol misuse, adolescent mental health problems and signposting young people to relevant services. Keeping up to date with safeguarding legislation and guidelines is also recommended.

Panel 3: The Fraser assessment

- The young person will understand the professional's advice
- The young person cannot be persuaded to inform their parents
- The young person is likely to begin, or to continue having, sexual intercourse with or without contraceptive treatment
- Unless the young person receives contraceptive treatment, their physical or mental health, or both, are likely to suffer
- The young person's best interests require them to receive contraceptive advice or treatment with or without parental consent

Collaborative working

It goes without saying that developing good, supportive working relationships between the paediatric team and identified adult team is the key to a smoother transition and transfer over to adult services. Providing a service to adolescents can be very challenging, and sharing decision-making and supporting colleagues makes all the difference. It is important to recognise the different approaches to care management between paediatric and adult services. Paediatric team approaches tend to be more paternalistic, with better multidisciplinary resources, whereas adult HIV services seem to be under pressure to provide a more consumer-orientated model of care, with increasing numbers of patients but without the financial or staffing resources to be able to provide the service that the team may want. With this in mind, providing a service 'that gets it right' and aims to bridge this gap can be very challenging for both teams.

Reflection

Within the past 8 years, HIV-positive adolescents have been transferring over from paediatric to adult services. Some larger centres have had the luxury of developing young person clinics to help with this transition in later adolescence, and with this have been able to find out from young people themselves what works and doesn't work to help shape the services for those on their way. It is important to share this information and experience with our colleagues, and work collaboratively to get it right for young people. HYPNet is a growing group of health and social care workers from tertiary and primary care, and the voluntary sector who are dedicated to improving the transition experience for young people. For more information, please go to www.hypnet.org.uk.

In my experience, it is a privilege to work closely with this group of young people.

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Direct observation of therapy: a case study

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Introduction

Antiretroviral therapy (ART) has significantly reduced mortality and morbidity in HIV-infected children. Its success, however, depends upon the level of patient adherence to medication. As adherence decreases, HIV viral load and the risk of progression to AIDS increases, as does the risk of the emergence of drug-resistant HIV.

Paediatrics has its own unique challenges when commencing ART. Many factors can affect concordance. The practitioner must consider the family holistically, as parents' understanding of HIV and their own beliefs can affect the child's adherence to medication [1].

The following case study aims to highlight a collaborative approach to direct observation of treatment (DOT). DOT has been a multifaceted approach to TB therapy for many years; however, there is not a great deal of literature on DOT in HIV-infected children [2].

Background

A 14-year-old boy presented to our clinic having been dispersed to Liverpool from London. He was already known to be HIV-infected. His CD4 cell count was 180 copies/ml and therefore treatment was discussed with the child and his family. Over many weeks, home visits were made by myself and my colleague to discuss medication and the importance of adherence. It was important that there was a clear understanding of the reasons for treatment and the commitment needed to achieve concordance.

Once we felt that the family was ready to take on the commitment of ART, a first-line regimen of once-daily Kivexa (abacavir and lamivudine) plus efavirenz was commenced. Treatment appeared to be successful as an undetectable viral load was achieved within 3 months of treatment.

However, 12 months later, blood taken for therapeutic drug monitoring during a routine clinic visit showed that the plasma level of efavirenz was undetectable. Therapeutic drug monitoring was carried out as the HIV viral load had risen to 3846 copies/ml. On questioning, the child and mother maintained that no drug doses had been missed. Although the test was repeated in case of a laboratory error, efavirenz remained undetectable.

A home visit was arranged to discuss concordance with the child and mother. It was found that the child had been given responsibility for

administering his own medication and quite often he would miss two or three doses a week. Although he would on occasion forget, another reason given for missed doses was that 'taking medication was not for him'.

The child's viral load was sent for resistance testing and he was found to have the K103N mutation, and the virus would now be resistant to treatment with efavirenz. Treatment was stopped and advice sought from our lead centre in London. As a Trust that cares for HIV-infected children we are part of the Children's HIV Network, which enables our centre to access advice and support from a London-based tertiary centre.

CNS involvement

It was noted that the child had poor memory and cognitive delay. His attainment at school had regressed and he had difficulty in concentrating.

Neurodevelopmental delay in children can manifest itself as deficits in attentional focus and executive functioning, which refers to one's ability to direct actions to actively solve a problem [3]. HIV encephalopathy can be defined as [3]:

- Failure to attain, or loss of developmental milestones or intellectual ability;
- Progressive impaired brain growth;
- Acquired symmetrical motor deficit;
- Paresis;
- Pathological reflexes;
- Ataxia and/or gait disturbances.

Owing to these findings, an MRI scan of the child's head was performed as well as a lumbar puncture to compare the HIV viral load in blood and cerebral spinal fluid (CSF). The conclusions drawn from the scan were that periventricular white matter appearances were non-specific and non-acute; however, they may represent previous ischaemic changes secondary to vasculopathy or early HIV encephalopathy. The radiologist requested a cerebral angiogram to aid diagnosis, as children with advanced HIV disease can be at an increased risk of suffering strokes caused by the effects of HIV on the vessels of the brain [3]. We await the results of the angiogram.

When comparing results from HIV viral load in blood and CSF, it was found that the viral load in CSF was higher than that in blood and thus was another indication of HIV encephalopathy.

New regimen

Following our clinical findings, it was imperative that a new antiretroviral regimen was commenced. Treatment with antiretroviral medications and early intervention programmes for children with neurological impairment can help mitigate the symptoms and improve the course of HIV encephalopathy [3]. Again expert advice was sought from our colleagues in London. The new regimen would need to have drugs that penetrated the CNS. The new regimen consisted of ritonavir-boosted darunavir and Trizivir (abacavir, lamivudine and zidovudine). Ideally, a once-daily regimen would have been given, however, Trizivir was chosen as it includes zidovudine, which penetrates the blood-brain barrier [4]. Zidovudine has a high CNS penetration-effectiveness (CPE) score, which illustrates the effectiveness of drug penetration into the CSF. The CPE score represents a step towards the identification of a clinically useful approach to estimating HAART ability to improve cognition [5].

Barriers to initiating treatment

As we were now commencing a second-line regimen, it was important to ensure good adherence to the new regimen. The child already had clinical signs of HIV encephalopathy and had admitted to not wanting to take medication. A referral was made to psychological services for assessment and then discussion took place with the child and mother to see how we could administer treatment successfully.

As a team, we felt that treatment should be supervised: the child had already failed his first-line regimen after only 12 months. This concept was discussed with the child and family and they agreed to supervision.

Direct observation of treatment

The children's community team at Alder Hey works with families that have acute and chronic needs. Following discussion, this team agreed to assist with DOT. A contract of care was drawn up in conjunction with the child and mother, outlining the role the nursing team would have and also what would be expected of them. The contract was placed in a folder that was kept in the child's home. Each time nurses attended the home they would document their visit. The information documented included the time medication had been given and how well it was tolerated. The community nursing team did not wear uniforms, therefore reducing the risk of stigma and disclosure when visiting the home.

The members of the community team had little experience of HIV infection, therefore teaching sessions were arranged and team members were invited to attend our HIV clinics on a weekly basis. As this was a new initiative, reviews were held every 2 weeks to discuss any problems or concerns.

Our aim in the long term was to establish a routine for the mother and child. As HIV is a chronic illness that requires life-long medication it was important to empower the family to take on this role themselves following the period of supervision. We did not want to encourage removal of individual responsibility [6].

At present we are reducing the number of visits by the community team to the home. The child's mother administers the medication in the evening, whilst the morning dose is given by nurse specialists. Over the coming weeks we will reduce the visits until the mother is confident administering treatment herself.

Medication has been tolerated very well. Darunavir levels 1 month post initiation of treatment were within therapeutic range and viral load was <400 copies/ml. At present, CD4 cell count is 180 cells/mm³ and at 3 months post initiation of treatment we will repeat immunological and viral screening.

No cognitive improvement has yet been seen; however, regular neurology and psychology follow-up will monitor progress.

Conclusion

Direct observation of treatment in HIV-infected children can decrease the incidence of mortality and morbidity. However, factors that affect concordance must be analysed as DOT is not a long-term solution. Families should be supported and empowered by the multidisciplinary team, so that in the long term they are able to successfully administer treatment themselves.

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CHIVA update

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Introduction

CHIVA (Children's HIV Association of the UK and Ireland) grew from the paediatric section of the British HIV Association (BHIVA) and was established as an independent organisation in 2002. At this time, an executive committee was set up and CHIVA started running conferences in parallel with BHIVA's autumn conferences. In 2007 CHIVA organised its first independent conference and in 2008 became a registered charity.

Geographically, CHIVA works in England, Wales, Scotland, Northern Ireland and the Republic of Ireland. The current populations served are children infected with HIV, children affected by HIV, and the families of these children.

CHIVA's main functions are developing guidelines and standards of care for children and families with HIV, acting as a resource for relevant national organisations and organising the two national conferences. In addition, in the last few years, CHIVA has been developing various projects. These are: the website, the summer camp and the youth committee.

In this article, we update you on the most recent conference and bring you the latest news from the different projects.

The 4th Annual CHIVA Conference

The 4th annual conference 'Paediatric HIV: Back to Basics' was held in Brighton in May and hosted by Dr Katy Fidler (Royal Alexandra Children's Hospital, Brighton). There were 150 attendees including three paediatricians from Africa, sponsored by Abbott. Next year these sponsored international spaces will be opened up to all healthcare professionals. Highlights included guest lectures from Professor Saye Khoo on 'Understanding pharmacokinetics and therapeutic drug monitoring of current antiretroviral drugs', a lecture by Reverend Trevor Thurston-Smith entitled, 'Faith: friend or foe?', and progress updates from the newly formed youth committee. All presentations from the conference will be available on the website (at www.chiva.org.uk/health/conferences).

The CHIVA website project

A consultation conducted by the Elton John AIDS Foundation (EJAF) with the Children's HIV Sector in March 2008 clearly indicated the need for a 'one-

stop shop' relating to all aspects of children and HIV in the UK. Due to the wide geographical distribution of infants, children and young people with HIV, it was agreed that a web-based information resource would best support the needs of this population [1]. This was the impetus for the successful website funding bid to EJAF. This three-year project will address the needs identified by young people, families and practitioners by using a community development/participatory approach to gather and present this information on the website.

The website project aims to bring all current work and resources together to signpost children, young people, families and practitioners to appropriate information, resources and services. It will also identify what work and resources are required to fill existing gaps.

Please visit the website regularly, to see the developments and improvements as they occur.

Secure site for HIV-positive young people

The first area of the website will be a separate, password-protected site for HIV-positive young people between 13 and 18. Our direct work with this group, and conversations with practitioners prior to the project, highlighted the need for a place they could go to find out detailed information specific to their experiences, where they would be able to ask questions and communicate with their peers [2].

This aspect of our project has engaged with two groups of HIV-infected young people. The first group has developed site maps and content for the web pages including extensive critiques (sometimes damning) of the initial designs presented. The second group has been trained to carry out interviews and has been gathering oral testimonies from parents, professionals and other young people – a few famous people have also agreed to be interviewed. Additionally, the structures for three short films have been agreed, to be carried on different parts of the site. Our aim is that this password-secure site will be both a source of detailed information and a place where young people can hear each others' experiences, share common problems, and establish a virtual community to combat feelings of isolation.

This section will go live by the end of September: please contact CHIVA if you need passwords for any patients in your clinics.

CHIVA family

Currently, there are very limited resources available to support parents in talking to their infected and affected children about HIV. Parents feel lost and isolated, and for many the impact leads to them avoiding any conversation about HIV. This can have negative and sometimes dangerous effects: some positive young people are not informed of their diagnosis until late in their teens; children are not being tested for HIV once a parent acquires a positive diagnosis; and affected children are not being told about HIV, including cases where they care for a parent; and, after disclosure has occurred, many children and young people have reported that they feel unable to talk about HIV with their parent(s) [1,3].

All these aspects cause huge amounts of stress on the family and can create many problems for everyone involved, as well as limiting the family's accessing of external support.

This part of the project has engaged with parents in focus groups to find out what information will help them through these difficult issues. The site will include bulletin boards and personal testimonies to enable parents to speak to each other and share experiences. Our aim is to support the 'skilling up' of parents so that they can offer their children the best care and support through this process.

This part of the site will be launched at the end of the year.

CHIVA youth: HIV-affected children and young people

Due to parents' fear of talking to their children about HIV, many children do not know the status of their parents or siblings – yet they are aware that there is something different about their families. They may take on caring roles for both younger siblings and parents, but it has been shown that they do not access vital support provided by young carers' services [4]. Even after official disclosure, the lack of information available and a lack of a place to ask questions mean that, at the very least, these children can feel isolated, alone and scared of what will happen to their parent(s) and subsequently themselves [5]. This can lead to adverse reactions such as deterioration in behaviour, poor performance at school – and in some cases family breakdown.

This project will strive to fill some of these gaps by working directly with HIV-affected young people to produce young-person-friendly information and signposting, as well as facilities to ask questions and a bulletin board to communicate with peers. Our aim is that this site will be able to answer questions and present information by and for affected young people so they understand the HIV diagnosis of their parents or siblings.

Additionally, research shows that children and young people living in the UK, who are outside families with HIV, have little or no understanding of HIV apart from its being a sexually transmitted disease [6]. This lack of knowledge and empathy means that children and young people living with HIV have to keep this secret from their peers. In the long term it also means another generation of people will grow up ignorant of HIV, thus continuing the discrimination against people living with HIV (PLWH).

Therefore, this area of the website will combine the needs of HIV-affected youth and those with an interest in the issues facing their peers living with HIV.

This part of the project will go live in September 2011.

CHIVA healthcare

This project aims to increase the scope, range and rigour of the guidelines available on the website and present them in a format that will be immediately applicable in the clinical setting, therefore maximising their practical application. The guideline process has been formalised with the initiation of a 'Document Group' which ensures all guidelines on the website are peer reviewed, and representative of best practice and the very latest information. The aim is that this will support high standards of care across the UK (in partnership with the CHIVA Networks section below) and help healthcare professionals optimise the health potential of children and young people with HIV.

Guidelines for 2010–2011 are in the process of being reviewed.

CHIVA networks

When they work well, networks lead to better outcomes for children and their families, both in health, peer support and meeting the psychosocial needs of children and young people living with HIV as they promote joint working and multidisciplinary support. This part of the project has set up a professionals' database to ease communication, and a notice board to help support development, involvement and dissemination of best practice.

The networks site as it appears currently is going to be redesigned to correspond with the new CHIVA standards. It will include a much more comprehensive database of professionals.

The plan is for the new networks site to go live by September.

CHIVA support: third sector

Our research has found that, whilst some third-sector organisations are very experienced and knowledgeable, others are relatively new to the field or do not currently consider the needs of a family when offering services to an adult [7]. This

inconsistency in the scope and standards of provision means that services for children, young people and families, particularly around disclosure and post-disclosure support, are either not available, or available to variable standards. Consequently some children and families can become very isolated as the impact of HIV becomes overwhelming. This can lead to increased need for interventions from statutory services, increased mental health issues and increased family breakdown.

As part of this project, we will gather all current practice and resources and house them in one virtual location. We will also work with the sector to set an agreed gold standard for services supporting children and families with HIV, with the aim of improving practice and therefore enhancing the services provided for children and families.

This part will go live in March 2011.

CHIVA support: non-HIV children and families sector

There is very little awareness of the issues faced by children and families living with HIV, and of the importance of confidentiality around HIV in the universal children's sector services. This lack of understanding means that many services are not accessible to HIV-infected and -affected young people when they need support. The impact of this is that most HIV-infected and -affected young people have nowhere to turn in times of crisis relating to HIV, or feel that they can not be fully open and honest as they fear breaches in confidentiality [8].

This aspect of the project will run a public relations exercise with the focus on universal children's services. This will entail producing a virtual library of resources specifically selected to highlight these pertinent issues across children's services and then bring together key stakeholders to advise on a strategy to raise the profile and the uptake of these resources. The aim of this aspect of the project is to raise awareness in the non-HIV children's sector (universal sector) and increase knowledge and use of the site, therefore promoting 'HIV-friendly' practice in this sector.

This part will go live in March 2011.

Summer camp

CHIVA's first summer camp, for 100 HIV-positive young people, will be running from 15 to 19 August 2010 in West Sussex. All places are free, as the camp has received funding from the Elton John AIDS Foundation and Pfizer.

The camp will combine structured workshops covering issues related to living with HIV, outward-bound activities designed to develop confidence and overcome fears, and social and leisure activities. By attending the camp, these young people will have the opportunity to develop much-needed peer relationships, which they will be able to sustain beyond the camp experience. Feedback

from previous breaks run by CHIVA has shown that this can be life changing for the young people concerned, with huge improvements in wellbeing and self-esteem reported. In turn, this can lead to better self-care, for example medication adherence, and also educational attainment and aspirations [2].

We had an overwhelming response to our adverts for recruiting volunteers, with an extremely high standard of applicants including non-HIV paediatric healthcare providers, social workers, children's rights leads and HIV activists. Forty volunteers have been selected and will be attending a day and night training session. Additionally, 13 HIV-positive 18-24-year-olds signed up to be camp leaders.

Youth committee

To ensure that young people have a voice and exert influence in the decisions that affect their lives, a youth committee for young people with HIV has been set up. The first meeting was held on the Thursday before the conference, during which the eight founding members agreed their roles, and the aims of the committee. The youth committee attended the 4th annual conference, with one member presenting a paper from some research she undertook on transition, and three others presenting project updates.

Conclusion

These are exciting times for CHIVA as it expands beyond its former role of conference-organising and advice. If you want to get involved in any of the projects, please don't hesitate to contact us at getinvolved@chiva.org.uk

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Understanding Zulu beliefs and customs in relation to HIV

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Introduction

Since November 2003, the South African government has provided a national antiretroviral rollout programme offering free antiretroviral therapy to all its HIV-positive citizens [1].

A fundamental issue of the rollout has always been to ensure that drug regimens are adhered to well. Poor compliance to therapy leads to drug-resistant HIV, which has both human and financial implications, as drug regimens must then be altered and healthcare management becomes more complicated. In August 2004, the Children's HIV Association of the UK and Ireland (CHIVA) assisted the KwaZulu Natal (KZN) paediatric rollout in a collaborative project together with the University of KwaZulu Natal and the Department of Health of KZN.

As part of the CHIVA/KZN project I went out in September 2004, and have continued to work exclusively in KZN. During my visits I became acutely aware of the strong Zulu culture and traditions that still influence health perceptions, the seeking of medical care and uptake of therapy, both conventional and traditional. In 2006, I was given written permission from KZN and approval from Brunel University to undertake a small project for my MSc dissertation, to learn more about rural Zulu beliefs regarding HIV.

Context

In 2007 the total population of South Africa was 47.9 million people, of whom 18.3 million were children under 18 years of age [2]; and by 2008 an estimated 5.2 million people were living with HIV. South Africa is a culturally diffuse nation; concepts and definitions of what constitutes illness or disease often do not have the same meaning as biomedical definitions. Use of traditional medicine remains widespread in resource-poor countries, while the use of complementary and alternative health practices is increasing in resource-rich countries.

KwaZulu Natal is one of the nine South African provinces and has a population of just over 10 million people. It is also the province that has consistently had the highest burden of HIV, with prevalence in excess of 35% since 2002 [3]. There are many factors that contribute to this predicament: gender inequality, violence, unemployment far above the national average,

and the fact that poverty is rising more rapidly in KZN than in other provinces. The pandemic is expected to peak around 2010; however, the predicted loss of life in KZN due to HIV/AIDS is staggering, with the adult population possibly being depleted by two-fifths [4].

Demographic settings

Two rural hospitals were chosen, as I had visited both several times over the years. Permission was given by the lead paediatricians involved in the HIV clinics. The most pressing problems in these rural areas are poverty and the growing HIV/AIDS epidemic.

St Apollinaris Hospital originally opened in 1888 as a mission hospital and remained so until 1990 when it was taken over by the Provincial Government. There are 155 beds and it serves a population of about 150,000 people from the surrounding rural area. The nearest tertiary referral hospital is Grey's Hospital in Pietermaritzburg, 90 km away and emergencies have to be taken there by helicopter.

Appelsbosch Hospital also started off as a mission hospital and was taken over by the Provincial Government. It has 183 beds and serves a population of about 170,000 people. Grey's Hospital is also its closest tertiary referral centre and is 35 km away but accessible by tarmac road.

Some understanding of current indigenous beliefs and customs will greatly improve outcomes in international health work; however, it must be acknowledged that cultures are never static or homogenous, and generalisations can lead to misunderstandings and prejudice [5].

The amaZulu are named after their chief, Malandela. The name Zulu means 'Heaven', and when Malandela started his own chieftaincy, he

Table 1: Zulu culture and health beliefs

Zulu vocabulary

amaZulu	Zulu race/nation
izangoma	divine healers
izingcabo	traditional incisions
KwaZulu	'place of Heaven'
lobola	custom of groom dowry
muti	traditional medicines
ukusoma	'high sex'
umhlanga	virginity testing
Zulu	'Heaven'

named the area in which he settled KwaZulu, or 'Place of Heaven' [6]. The Zulu is the largest ethnic group in South Africa and retain a monarchy; King Goodwill Zwelithini is the eighth monarch and present head of the Zulu nation. As custodian of Zulu traditions and customs, he plays an important role in the internal governing of the homeland and acts as a voice for his people on an international level. The Zulu have also had their own political party since 1975, the Inkatha Freedom Party (IFP), founded and led by Chief Mangosuthu Gatsha Buthelezi [7].

Land and livestock remain vital to this patrilineal society, to their sense of self and for survival; however, few nowadays can afford to keep cattle, which still symbolise the wealth of a family and are used for lobola, the custom by which a dowry is paid by the bridegroom's family for a wife. For Zulu women there is power inequity, as they are often financially dependent and expected to be tolerant of gender-specific sexual behaviours.

Procreation is highly valued in African cultures and so in Zulu culture, and involves lineage, ancestors, religion and the fulfilment of family and gender roles [7,8]. Children in Zulu families are taught to respect their elders. The only people children treat as equals are other children of similar age and sex [7].

Ancestral beliefs and traditional healers

It is customary in many traditional African cultures to attribute illness or misfortune to spirits, mystic forces and restless ancestors. The Zulu believe that divine healers, or izangoma, have supernatural powers and can communicate with ancestral spirits on their behalf, and also protect them from witchcraft. As izangoma share the same history and culture as those consulting them, they provide the crucial link between the physical world and afterworld [9]. Izangoma are chosen by the ancestors. In order to ensure supernatural healing powers, traditional medicines (known as muti) must be harvested and prepared by the izangoma in accordance with specific rules and rituals and therefore cannot be commercially produced [10].

Methodology

This fieldwork involved carrying out semi-structured interviews over several weeks with children and adults, with the assistance of a Zulu-speaking interpreter I employed at each rural site. The semi-structured interviews were based on two sets of questions, one asking about general health observations, the second about HIV-related beliefs and observations.

Seeking and giving consent is an extremely complex process [11]. Because signing consent forms caused confusion and suspicion amongst the Zulu, I settled for verbal consent given after the

interpreters outlined the purpose of my study, and guaranteed anonymity. I am satisfied that this consent was informed and freely given. Children were also asked to verbally consent in the presence of either a parent or guardian, and only appropriate questions were asked. There are ethical and moral implications when working with children; however, progressively more research is now carried out involving children as they are no longer seen as 'simply passive objects dependent on adults, but are competent social actors that make sense of and actively contribute to their environment' [12].

In total, 51 people were interviewed from the two rural hospital sites. I also was able to interview two sangomas, two healthcare personnel, a large group of NGO carers who provide home-based care and support for HIV-positive people in the community, and a small cohort from a rural church. Children and young people were classified as those from birth to 25 years of age, as this was in line with the Zulu perception of pre-adulthood.

Findings

Most people affirmed that HIV cannot be cured, and either considered it a normal disease or naturally occurring phenomenon originating in monkeys or apes, which was then contracted by humans through having sex with the animals [13]. However, 25% of interviewees considered HIV had been created and spread around to infect black people with the aim of reducing their numbers. Several mentioned Dr Wouter Basson, who was described as the 'archetypical evil scientist' and assigned by the apartheid government to eliminate black people. On researching, I found Dr Basson did exist, and that in October 1999 he was tried in a criminal court on multiple counts of fraud, murder, conspiracy to murder, and possession of illicit drugs [14].

Almost every single adult and youth interviewed agreed that the highest risk of acquiring HIV was sexually, and that the youth were the most vulnerable to HIV infection, with young women coming out slightly ahead of young men. The 'Abstain, Be faithful and Condomize' message was quoted; however, few believed being faithful was sufficient. Curbing sexual desires was considered necessary by the adults and some of the youth, and many adults lamented that the Zulu tradition of non-penetrative sex (ukusoma), taught to young women by their mothers, has today been mostly abandoned in favour of penetrative sex [15].

The risk from exposure to blood was linked closely with the use of razors and having traditional incisions (izingcabo), and most interviewed believed strongly that avoiding touching 'dirty' blood or open sores, and wearing gloves if needed, would give protection from HIV. This links with Zulu notions of pollution and vulnerability [8].

The question 'who do you go to first when you are ill?' assessed the use of traditional healers and muti. It was probably the question hardest to get truthful answers to, owing the very strict antiretroviral rollout policy that stated people could use ART or muti, but absolutely not both. Results from a 2002 study in KZN showed that 70% of patients would consult traditional healers first over health matters. The effectiveness of traditional healers is, however, unknown, mainly because the products they administer (plant and animal matter) are rarely scientifically researched and are poorly regulated [16].

Of the 33 people who did answer this question, 17 specifically said they had used traditional healers, and 11 were still using traditional healing in some way or another. Efforts to integrate izangoma into HIV health initiatives in KZN have been resourced by both provincial and NGO funds [17].

Discussion and summary

Children's position in Zulu society is constrained by the subordinate status granted to them by society generally, and by their position in Zulu culture. This, coupled with their cultural reserve, made interviewing the children harder than anticipated [18].

There were some other obvious reasons that will have influenced the process: my own ethnicity, gender, awareness of cultural norms and beliefs, and inability to speak the Zulu language. However, youths and adults were willing to engage, and were frank and informative.

Adults mentioned fear of imminent or early death as the worst thing about living with HIV. Stigma was also mentioned, but there seemed some confusion as to what constituted stigma or discrimination. Witchcraft-related violence in South Africa still continues despite political intervention to dissuade people from making allegations. The main fatalities of witchcraft-related violence have been, and still are, women, especially amongst the elderly and children [19].

Because of the overwhelming effects of HIV/AIDS, the Zulu people follow all avenues of treatment for HIV and its symptoms, including biomedical, traditional and spiritual conduits.

There are dangers to paying lip service to indigenous beliefs and the importance of culture without looking carefully at norms and practices that increase vulnerability to HIV. Whilst the practice of umhlanga (virginity testing) amongst Zulus is making a comeback, it has met with opposition from the Children's Rights movement as it places the burden of sexual responsibility on girls [20]. However, the far more serious problem of gender-based violence in South Africa needs urgent attention. Recent statistics show that 71% of girls

have had sex against their will, while many women continue to experience sexual violence by an intimate partner. The problem is the deeply entrenched ideas underlying the construct of masculinity in South Africa, which condones violent and sexually violent behaviours [20,21].

Since 2006, the South African government has been working towards the official acceptance, recognition and institutionalisation of African traditional medicine. A draft policy in 2008 was aimed at establishing a system to regulate, register, and license traditional health practitioners, and stipulated formal training of such practitioners and their products [22]. However 'traditional medicine' covers a wide variety of therapies and practices, and enormous effort, trust and respect is needed for both indigenous and allopathic medicine practitioners to work together for the wellbeing of children and adults with HIV/AIDS. Attempts to curb indigenous medicine and its practitioners by using legislation will simply make it covert. It will take time for the concept of HIV as a manageable chronic condition to take shape, and become incorporated into Zulu cultural and religious ideology.

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NHIVNA update

■ This will be my last update as Chair of NHIVNA and my chance to say thanks and goodbye, and to wish you all well for the future.

My involvement with NHIVNA started many years before I was elected Chair and I will be sad to step down when my 3-year term comes to an end this summer.

For many years, I have been proud to be part of this group, which I feel has provided me, and I hope many of you with clarity, focus and a common goal, as well as companionship.

It can be easy for some of us older folk to feel we are NHIVNA, but what I feel is incredibly important, is that NHIVNA is a living and breathing organisation. It is important we continue spread the word, to welcome and encourage new faces to the group in order to remain vibrant and relevant.

It has been great to see increased attendance at the conference each and every year, and I have been overawed by the number and quality of abstracts and papers submitted.

The three years went by so quickly and it's fair to say that I didn't complete all the things I wanted to do in that time. I'd wanted to audit the scholarship programme and this will now be undertaken by others.

But NHIVNA is in good hands with a growing and dedicated committee, a clear vision and growing membership. I would encourage any of you to put yourself forward for contribution or committee work, as diversity and change increase the richness and quality of the organisation overall.

I will still be proud to represent the HIV services in Scotland (so you haven't gotten rid of this old Scot yet!)

I wish the incoming Chair all the very best and look forward to catching up with many of you at conferences in future years, meanwhile thanks for all the support, contributions and good times – keep up the good work.

Sheila Morris, Chair, NHIVNA