ORIGINAL ARTICLES

A family clinic—optimising care for HIV infected children and their families

Diana M Gibb, Janet Masters, Delane Shingadia, Sue Trickett, Nigel Klein, Candy Duggan, Vas Novelli, Danielle Mercey

Abstract

A family clinic providing specialist paediatric and adult medical, testing, counselling, and terminal care services for families living with HIV was set up at a paediatric tertiary care hospital in London in 1991. During the first five years, until April 1996, 185 children from 149 families attended, including 119 infected children, of whom 32 have died. Only 5% of mothers were born in the UK; the rest were born in 24 different countries, the majority in sub-Saharan Africa. Less than a quarter of children were cared for by both parents, 61% by mothers alone, and 11% by guardians or foster parents. Of the adult attendees, 76% were women, and more than half were untested when they first attended the clinic. Provision of a family planning service within the family clinic was initiated as a result of women presenting with unplanned pregnancies. Shared care with local clinics is increasing, but with the complexity around the management of paediatric HIV infection, particularly with regard to antiretroviral treatments, there is need for continued specialist input. Coordination among specialist and locally based family services is required to provide flexible, accessible, and up to date care for families living with HIV infection in London.

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Most paediatric HIV infection is due to mother to child transmission, and the prevalence of HIV infection in pregnant women in the UK has doubled between 1990 and 1995. It is highest in inner London where 0.26% of pregnant women were infected in 1995.¹ By April 1996, 276 of the 389 (71%) children with HIV infection or AIDS reported to the combined obstetric and paediatric national confidential registers were from London, 80% of whom were born to women who had acquired their infection in sub-Saharan Africa.²

In London, detection of HIV infection in previously undiagnosed pregnant women is only around 10%,³ and an infected child is frequently the first family member to be diagnosed as a result of developing HIV symptoms or AIDS.⁴ In 1991, referrals of newly diagnosed symptomatic HIV infected children to the infectious disease unit at the Great Ormond Street Hospital for Children NHS Trust (GOS) were increasing, and there was difficulty in obtaining counselling and diagnostic and medical services for parents at a time when they had recently learnt of their child's diagnosis and were unwilling to be referred to another institution. Many families also face multiple psychosocial problems, including uncertain immigration status, low income, and poor or temporary housing. Some have experienced the trauma of war in their countries of origin, and English may not be their first or second language. Overridingly, and in contrast with many other chronic illnesses in childhood, the stigma associated with HIV results in families living with secrecy, in isolation, and in fear of breach of confidentiality to others at home and in their community.

A questionnaire survey of parents of HIV infected children attending GOS in 1991 showed that they experienced problems attending genitourinary clinics for their own care because of the lack of facilities for accompanying children. Single mothers in particular found it difficult to keep appointments for themselves and their children at different hospitals. Colleagues from the genitourinary clinic at the nearby Middlesex Hospital also reported that HIV infected women attending their service were increasingly asking for advice about testing and care of their children, and about future pregnancies.

For all these reasons, an HIV family clinic was set up at GOS in May 1991 to provide coordinated medical, social, and psychological care for families with HIV in a child centred, welcoming environment. In this paper, we describe the clinic organisation and characteristics of families who have attended. Issues that have arisen over the first five years, and ways in which family based services might develop in the future, are discussed.

Department of
Infectious Diseases,
Great Ormond Street
Hospital for Children
NHS Trust, London
D M Gibb
D Shingadia
S Trickett
N Klein
C Duggan
V Novelli

Department of
Epidemiology and
Biostatistics,
Institute of Child
Health, London
J Masters

Department of
Sexually Transmitted
Diseases,
UCL Medical School,
London
D Mercey

Correspondence to:
Dr Diana M Gibb,
Department of Epidemiology
and Biostatistics,
Institute of Child Health,
30 Guilford Street,
London WC1N 1EH.

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Table 1 Services at the GOS HIV family clinic

Type of service	Personnel	Details
Medical	Paediatric: HIV specialist Subspecialist Dietitian Physiotherapist	Clinical care for children; expertise in antiretroviral treatment For example, respiratory, dental, gastroenterology, dermatology, neurodevelopmental assessments
	Adult: HIV specialist Nurse	Clinical care for parents
Counselling and testing	Paediatric: Nurse counsellor Social worker Psychologist HIV specialist	For parents, children, other family members, pregnant women
	Adult: Health advisor HIV specialist	
Preventative health	Paediatric team	Immunisations, dietary advice, dental care, social assessment
	Adult: Health advisor Nurse	Sexual health advice for parents; condoms; contraceptive service for women
Training and liaison	All team members	Telephone advice; liaison and information for community groups; outreach clinics
Terminal and respite care	Inpatient nursing staff	Liaison between paediatric and adult inpatient nursing staff
	Social worker, psychologist Symptom care team	Planning for childcare if parents die Allowing terminal care at home if parents wish
Research	All paediatric team members	Paediatric advisory and training role at Mildmay hospice
	Paediatricians Research nurse	Including participation in multicentre clinical trials

Setting up the family clinic

A joint protocol was developed by members of the paediatric infectious diseases team at GOS and a genitourinary adult physician at the Middlesex Hospital (subsequently the Mortimer Market Centre). Agreements were made with outpatient, pharmacy, and radiology departments at GOS to provide services for the parents of HIV infected children. The clinic site in the new GOS outpatient department had the advantage of play areas and of being non-stigmatising (other paediatric outpatient clinics are held in parallel). Paediatricians specialising in infectious diseases, a nurse counsellor, psychologist, social worker, and physiotherapist formed the initial paediatric team and a genitourinary physician and health advisor saw the parents. A paediatric research nurse provided support and information to families of children enrolled in studies and clinical trials, and a part time data manager collected key data for audit purposes. A weekly preclinic meeting was established to provide a forum for coordination among team members. Professionals from referring institutions also attended, thus facilitating dissemination of expertise, planning of local care for families, and the setting up of shared care arrangements with local hospitals. In 1995, a paediatric dietitian, an adult nurse with a particular remit to provide contraceptive advice to women, and a

paediatric pharmacist joined the team. Arrangements were made for children to be seen by other subspecialties (for example, dentist and dermatologist) at the same outpatient visit, and for them to attend a clinic every two months with a paediatric respiratory specialist, which was set up for joint review of children with lymphocytic interstitial pneumonitis (LIP) and chronic lung disease. As children and parents became more unwell, the preclinic meeting also provided a forum for communicating decisions about inpatient and terminal care. Table 1 shows a summary of the family clinic services.

Results

SOCIAL CIRCUMSTANCES OF FAMILIES

One hundred and eighty five children from 149 families attended the clinic between May 1991 and April 1996. Only 5% of mothers were born in the UK, the rest came from 24 different countries, the majority in sub-Saharan Africa (table 2). Whereas 60% lived in inner London (mainly North Thames), 21% were referred from outside London. Referrals were from a wide spectrum of sources including paediatricians from district hospitals, genitourinary physicians, maternity units, social workers, general practitioners, and community HIV groups; self referrals also occurred.

Data on the family structure for 59 children from 56 families were available between April 1993 and 1996. In April 1996, only 14 (24%) children were cared for by both parents; 36 children (61%) were cared for solely by their mothers; two (3%) solely by their fathers and six (11%) by a guardian or foster carer. One grandmother was the sole carer and three others contributed significantly to child care in addition to a parent.

Twenty two of the 56 families (39%) had changed accommodation between April 1993 and April 1996, six from temporary to permanent accommodation, seven into special

Table 2 Last known area of residence by mother's country of birth

Mother's country of birth	Last known area of residence (number of women/families)			
	Inner London	Outer London	Rest of UK	Total (%)
UK	4	1	2	7 (5)
Uganda	44	8	4	56 (38)
Zaire	7	4	3	14 (9)
Other Africa*	24	9	5	38 (26)
Other world†	10	5	18	33 (22)
Not known	1	0	0	1 (1)
Total	90	27	32	149 (100)

*Zambia, Kenya, Nigeria, Angola, Tanzania, Ghana, Ivory Coast, Namibia, Burundi, Somalia, Cameroon, Congo, Zimbabwe, and South Africa.

†USA, Turkey, Romania, Columbia, Guadeloupe, Uruguay, Mauritius, India.

Table 3 Children attending the GOS family clinic

Status at 30 April 1996	No	Sex		Median age in years at presentation (range)	Ethnicity			Died
		Boy	Girl		Black African	White	Other	
Infected*	119	63	56	1.25 (0.003–12)	81	25	13	32
Uninfected†	55	26	29	1.75 (0–14)	38	8	9	n/a
Indeterminate	6	5	1	0.18 (0.04–0.74)	3	3	0	n/a
Untested‡	5	5	0	2.31 (0.07–3.98)	4	1	0	
Total	185	99	86	1.17 (0–14)	126	37	22	32

*Includes 32 deaths, five children who have gone abroad, seven who have transferred care and two who were lost to follow up.

†Includes 27 children referred under 18 months of age when their infection status was indeterminate.

‡Three are presumed infected.

housing because of HIV status, five because of a violent partner, and four because of the death of a parent.

CHILDREN ATTENDING THE CLINIC

Of the 185 children attending the clinic during the first five years, 119 were infected, 55 uninfected, and six were of indeterminate status; five remained untested at their parents' request (see table 3). Thirty two infected children had died, and 14 had gone abroad, transferred care, or were lost to follow up. Although the majority of families had only one infected child, five families had two and one had three infected children. Twenty seven (49%) of the uninfected children were referred at an early age and required follow up until infection status was determined. Of the five untested children, three were presumed to be infected due to the presence of clinical signs. The median age at presentation of infected children was 16 months, but the range was wide and 19% were initially referred after their fifth birthday.

When absence of infection is confirmed in children born to infected mothers, they are generally no longer followed up at the family clinic. Care for the parents continues with the same adult physician at the nearby adult clinic after a social worker assessment to ensure that plans for future child care are on the agenda for the family and other involved carers. Parents of children who die are also usually transferred to the adult clinic, but followed up by the same physician to ensure continuity of care.

PAEDIATRIC SERVICES

The number of consultations with paediatric team members has steadily increased over time. In 1991, an average of three children were seen by a paediatrician each week; this rose to 10 per week by early 1996. Between April 1995 and April 1996, 75 infected children regularly

attended the clinic, of whom 26 had AIDS, and the majority of the remainder had symptoms. Children without AIDS attended the clinic approximately every three months, whereas those with AIDS attended approximately every month. About a quarter of children were also seen at their local hospital, either on a shared care basis or in emergencies, and physiotherapy and special needs services for children with chronic lung disease and neurological problems were frequently provided through liaison with appropriate professionals in the community. Paediatric team members had additional consultations with families at times other than during the family clinic. For example, the time consuming nature of consultations with the social worker and psychologist necessitated appointments outside the clinic times, particularly for developmental assessments or interventions in behavioural or emotional problems of children and their families. The role of the nurse counsellor and social worker has shifted over time towards more liaison and support work with local service providers where families agree to referrals being made. Many families, however, do not want their status to be known outside the 'safety' of the clinic, with the result that they may not access specific services such as nursery placements, respite care, or rehousing. With increasing numbers of older children attending the clinic, an important role for the psychologist involves helping parents talk to their children about their HIV diagnosis.

Providing information and training for local professionals about paediatric HIV disease has become an important part of the work for all team members. A research nurse has been a consistent member of the team providing support and information for families enrolled in research projects, particularly those enrolled in multicentre clinical trials of antiretroviral treatments carried out by the Paediatric European Network for Treatment of AIDS (PENTA).

INPATIENT CARE

An increasing proportion of children admitted to the infectious diseases unit have HIV infection. Children can be admitted with a parent, but as yet there are no facilities for the care of a sick mother and sick child on the same site. When this arises, close liaison among paediatric and adult inpatient staff in the respective hospitals has enabled a sick mother and child to spend the maximum possible time together in one or other of these units.

Table 4 Inpatient admissions to GOS for children with AIDS for 30 children followed up between AIDS and death

AIDS indicator disease (n)	Median age in months at AIDS diagnosis (range)	Median age in months at death (range)	Hospital admissions per child per month with AIDS	Hospital days (PICU‡ days) per child per month with AIDS	Died	
					In hospital	At home
<i>P. carinii</i> pneumonia (11)*	5 (2–8)	11 (3–27)	0.5	8.3 (1.4)	8	2
Severe LIP/bacterial infections (4)	38.5 (3–88)	59.5 (17–198)	0.2	2 (0)	2	2
Other (13)	22 (5–94)	62 (12–112)	0.2	3.4 (0.07)	11	2
Total (28)†	8 (2–94)	31 (3–198)	0.26	3.9 (0.3)	21	6

*Data on hospital admissions not available for two children.

†Does not include two children whose notes were lost and two more children who died without AIDS diagnosis (one cot death at home at 6 months; one first bacterial meningitis infection at 13 months).

‡PICU = paediatric intensive care unit.

Table 5 Parents registered with adult physician

Status at 30 April 1996	No (%)	Sex		Reason for presentation			
		Men	Women	Child ill	Self ill	Antenatal	Other
Asymptomatic	45 (40)	8	37	20	5	5	15
Symptomatic	8 (7)	2	6	6	0	1	1
AIDS	6 (5)	3	3	1	2	0	3
Died	12 (11)	1	11	8	1	1	2
Uninfected	7 (6)	3	4	4	0	0	3
Untested	19 (17)	8	11	19	0	0	0
Transferred/lost to follow up	15 (14)	2	13	4	1	1	9
Total	112 (100)	27 (24)	85 (76)	62 (55)	9 (8)	8 (7)	33 (29)

Table 4 shows inpatient days per child per month, including days in intensive care, and the place of death for the 32 children followed up from their AIDS diagnosis until their death at GOS (up until April 1996). This is an underestimate of resource use as about a quarter of children were also admitted to other hospitals (not shown in table 5). For simplicity, AIDS indicator diseases have been divided into 'Pneumocystis carinii pneumonia' (with or without cytomegalovirus infection), 'lymphocytic interstitial pneumonia/severe recurrent bacterial infections', and 'other'. Two infants died without an AIDS diagnosis, one from cot death and one from a first bacterial infection. Children with *P. carinii* pneumonia had the highest rates of inpatient and intensive care stays. Most deaths (78%) occurred in hospital.

PARENTS ATTENDING THE CLINIC

One hundred and twelve adults registered at the clinic over the first five years, 76% of whom were mothers (table 5). The majority of the parents had not been tested for HIV when they first attended the clinic and 62 (55%) had their first HIV test after their child's diagnosis; nine (8%) were tested as a result of being unwell themselves and only eight (7%) had been diagnosed as a result of antenatal HIV testing. Some who had received medical care elsewhere transferred or shared care with the clinic for the convenience of attending at the same time as their child. By April 1996, 12% of adults had HIV related symptoms or AIDS, and a further 11% had died. Nineteen (17%) chose to remain untested, all of whom had a symptomatic infected child.

SERVICES FOR PARENTS

The average number of weekly consultations for parents with the adult physician doubled between 1991 and 1996. In 1995, an adult nurse joined the team to provide practical and psychological support to parents, and as nearly a third of adults also received some aspect of care at the adult clinic, to liaise between the two centres. Provision of a contraceptive service for women attending the clinic was initiated because 19 women reported 25 pregnancies, most of which were unplanned. Terminations were requested for 10.

Women diagnosed with HIV infection for the first time during pregnancy were also referred from the antenatal clinic.⁵ A visit to the clinic provides an opportunity for the prospective mother to meet clinic staff, and to discuss

interventions to prevent mother to child transmission, and follow up for her and her baby.

Discussion

There is no gold standard model of care for HIV infected children and their families. The appropriateness of different models will depend on the medical needs of individual family members and the social and cultural situations in which families find themselves. HIV infection often affects several family members with a condition which is complex and unprecedented in its ability to stigmatise. For these reasons, there is a strong argument for managing many aspects of the disease through services available to the whole family and coordinated on one site.^{6,7} This reduces the time, inconvenience, expense, and need for child care which exists if family members have to attend different appointments at several sites, and ensures better coordination among the different professionals involved. It has also been reported that families living with HIV infection in London prefer a family based model of care.⁸

A key reason for setting up a family clinic in a specialised children's hospital was the frequency with which the sick infected child presented to hospital from a family where no diagnosis of HIV infection had been made. This situation is likely to continue until there is a substantial increase in the detection of HIV infection in pregnant women, as currently fewer than 20% are diagnosed in pregnancy.^{3,9} Before the family clinic was established, parents would often focus on the sick child and ignore their own health, indefinitely deferring HIV testing and/or access to medical care. Data from the European Collaborative Study suggest that 15% of mothers die and 25% develop AIDS by their child's fifth birthday,¹⁰ but this situation could improve with the increasing use of new antiretroviral treatments. Medical care for parents is important, not only for themselves but for their infected and affected children.

Over a quarter of HIV infected children attending the clinic over the past five years have died. A third of these were very young and lived for only six months after developing *P. carinii* pneumonia. The other children died, however, after an intermittent and prolonged illness lasting two to three years. On average, about 12% of their time was spent as an inpatient which is similar to data reported by Mandalia *et al.*¹¹ Although most children died in hospital, nearly a quarter died at home, a situation made possible by involvement of a local hospice for families (the Mildmay Mission Hospital) which team members visit on a regular basis, and the symptom care team, originally set up to care for children dying at home of cancers and expanded to include children dying of HIV and AIDS.¹²

As vertically HIV infected children enter their teenage years, telling them their own and their parents' HIV diagnosis has become an increasingly important and difficult area for parents and professionals alike. Many parents wish to keep the diagnosis from their children for as long as possible, which poses ethical

dilemmas for team members, who are aware that children and young people need to be able to talk about their illness and to be involved in decisions about their treatment. The combined input from paediatric and adult health professionals and a social worker, in the setting of a family clinic, provides a good forum for addressing such issues with individual families. For older children who know their HIV diagnosis, the family clinic provides a situation for smooth transition from paediatric to adult services.

Since 1990, several centres in London have set up family HIV clinics. Some, like ours, are 'paediatric specialist' led and have developed as a result of sick infected children first presenting to their units.⁶ Others have arisen from the perceived need for a local community based clinic for children in families where adults (and particularly women) are already attending local genitourinary services.⁷ Both models of care are needed and should be complementary with shared care and outreach clinic arrangements to facilitate communication. At different stages of illness in different family members, attendance can be more community or more specialist based, depending on the situation and wishes of the family, as well as on the need for specialist input into medical management.

Treatment for HIV infected children is becoming increasingly complex, requiring more sophisticated outpatient facilities, including viral load monitoring and experience in managing complicated antiretroviral regimens. Licensing treatments for children lag behind those for adults, and paediatricians need to liaise with pharmaceutical companies to obtain compassionate access to paediatric treatments. Where possible, families and children should be invited to participate in multicentre clinical trials, for example those set up by PENTA, of antiretroviral treatments. At present in adult HIV services, there is a shift of resources from inpatient to more intensive outpatient based care as more triple antiretroviral combination treatments are used at earlier stages of the disease. The same is occurring in paediatric services as more treatments become available for children.

If women know their HIV status in pregnancy, they could benefit from interventions to reduce mother to child transmission. Already in the US and France, where uptake of antenatal HIV testing and use of zidovudine in pregnancy is high, the incidence of paediatric HIV infection and AIDS is decreasing.¹³ Early diagnosis and aggressive antiretroviral treatment for infected infants may also prove to be the best chance to substantially change the natural history of the disease.¹⁴ Implementing this will require, however, a high level of coordination among obstetricians, neonatologists, specialists in paediatric HIV, and virologists, as well as commitment from families. If mother to child transmission decreases in the UK, the small numbers of infected children requiring

intensive management would argue for more specialist led care with local implementation of detailed and frequently updated management guidelines.

Other conditions for which a family clinic model could be considered include genetic disorders and other infectious diseases where maternal infection is transferred perinatally. Genetic disorders, however, rarely cause the same degree of acute illness concurrently in several family members, and with most congenital infections only the infected child requires ongoing medical care. None has the degree of stigma found with HIV infection. An exception may be the emerging problem of hepatitis C infection. While the vertical transmission rate for hepatitis C virus is lower than that for HIV (unless the mother is coinfecting with HIV) and the incubation period even longer (making concurrent infection of child and parents less likely), diagnostic difficulties in early life and the future development of treatments which aim to eliminate the virus may mean that a model of care similar to that described in this paper will be required.

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