General practice and the care of children with HIV infection: 6 month prospective interview study

Mary Boulton, Eddy Beck, Sam Walters, David Miller

Editorial by Kidd

Department of Epidemiology and Public Health, Imperial College School of Medicine, London W2 1PG
Mary Boulton, *senior lecturer*
Eddy Beck, *senior lecturer*
David Miller, *emeritus professor*
Department of Paediatrics, Imperial College School of Medicine
Sam Walters, *senior lecturer*
Correspondence to: Dr Boulton m.boulton@ic.ac.uk

BMJ 1999;319:232–5

Abstract

Objectives To describe the use of primary care services by children infected with HIV and to explore the attitudes of their parents to the role of general practitioners in their children's care.
Design A 6 month prospective study. Quantitative analysis of "contact diaries" kept by parents; qualitative analysis of face to face interviews with parents.
Participants Parents of children receiving care at a regional referral centre in London.
Results Twenty four families (80% response rate) were recruited to the study. In 19 families the mother was black African. Half the children had been diagnosed with symptomatic HIV infection, half with AIDS. All the children were registered with a general practitioner who knew of the child's HIV infection. In five families there had initially been tensions in their relationship with their general practitioner but by the time of the study all but one family had established at least an "acceptable" relationship. Children with symptomatic HIV infection saw their general practitioner a mean of 7.5 times per patient year; for children with AIDS the figure was 5.8. Parents regarded the paediatric HIV team at the hospital as their primary source of medical care. Three factors constrained their use of general practice: their own anxieties about distinguishing "normal" symptoms from those related to HIV infection; their view that their general practitioner did not feel competent to treat HIV infected children; and their concerns about maintaining confidentiality in the surgery.
Conclusions Parents remain oriented towards the paediatric HIV team as their primary source of medical care and use general practice largely for routine prescriptions for their children. Any further development of the general practitioner's role will need to build on existing relationships with specialist providers and take account of parents' concerns.

website *e*xtra

Two further boxes appear on the BMJ's website

www.bmj.com

Introduction

In principle, general practitioners have a potentially important role in the care of people with HIV infection.[1–4] As advances in medical treatments mean that more people are living longer with HIV infection, a greater proportion of their care is expected to be shifted from specialist units based in hospital to the community. The end of "ring fenced" funding for specialist HIV services is likely to fuel this process and support the argument that general practitioners should become more closely involved in the care of their patients with HIV infection.[5]

Although children constitute an important group of patients in general practice, issues in the provision of care to children with HIV infection have remained largely unexplored. By the end of July 1998, 855 children had been identified as HIV positive,[6] and antenatal surveillance programmes suggest that this number is likely to increase.[7] Debate about the appropriate role for the general practitioner requires an understanding of how these children use general practice and the attitudes and concerns of their parents.

Sample and methods

The study was approved by the ethics committee for St Mary's Hospital, London.[8] Between 1 September 1993 and 31 December 1994 the paediatric HIV team at the hospital provided care to 64 children (in 60 families) who tested positive for HIV antibody, of whom 30 children (in 30 families) met the criteria for inclusion in the study: HIV infection confirmed, alive, living in south east England, and living with a carer well enough to be approached for interview.

Twenty four families (80%) agreed to take part in the study. Families were contacted up to six times over 6 months between October 1994 and May 1996. Parents were given a diary and asked to note their contacts with all health and social services; this information was collected at monthly intervals. In addition, an anthropologist carried out open ended, loosely structured interviews with parents in their homes. Personal interviews with a qualitative approach were used as the main method of data collection because of the difficult circumstances in which most of the families lived and the sensitivity of the study topics. As far as possible, information was collected through naturalistic conversations with parents, which allowed them to define issues in their own terms.

Twenty four families kept a "contacts diary" for at least 2 months; and 22 families completed at least one interview on the study topics. A total of 63 face to face interviews were carried out. When possible, these were tape recorded and later transcribed. Transcripts and field notes were analysed according to the methods of inductive analysis used in qualitative research.[9]

Results

Characteristics of the sample

The children were young (median (range) age 5 (1-12) years); 14 were girls. All but one (a Romanian orphan) had been infected through vertical transmission; 12 had been diagnosed with symptomatic HIV infection, 12 with AIDS. In 19 families the mother was black African. In at least six families one or both parents had already died from an AIDS related illness; half the families were headed by a single parent.

Registration, disclosure, and quality of relationship

At the time the study was carried out all the families were registered with a general practitioner, all of whom had been informed of the child's HIV infection. At least two families had not been registered with a local general practitioner at the time the child had been diagnosed, and five families reported considerable tensions in their relationship with their general practitioner around the time of diagnosis. This was most notable in those families in which the child had been the first member to be identified as HIV positive, generally after an extended period of unexplained illness that resulted in an emergency admission to hospital. Three families complained that, before the diagnosis was made, their general practitioner had treated them in an off hand way and had not taken their anxieties seriously; two families were upset by their general practitioner's attitude towards them once the diagnosis had been made and two were angry that their general practitioner had broken confidentiality in divulging the diagnosis to others. At least three families were unwilling to continue with their practice as a result. When families were not registered with a local practice or when they wished to change general practitioner, the paediatric HIV team had taken an active role in finding them an interested and supportive practice in their area and in facilitating the disclosure of their child's HIV infection.

General practitioners were often the only individuals locally who knew of the child's HIV infection and, when they expressed concern and offered to help, families greatly valued their support. Whatever their earlier experience, by the time the study was carried out six of the families described their relationship with their general practitioner as "very good" and the rest (with one exception) as at least acceptable.

Use of primary care services

The frequency of contact with general practitioners varied according to the stage of the child's disease. Children with symptomatic HIV infection saw their general practitioner a mean of 7.5 times per patient year (median (range) 2.7 (0 to 25.8)), whereas for children with AIDS the figures were 5.8 (2.1 (0 to 18.9)). By contrast, the use of hospital services, especially inpatient care, increased with increasing severity of HIV infection.[10]

The most common reason parents gave for contacting their general practitioner was to obtain repeat prescriptions for drugs prescribed by the paediatric HIV team. This often did not involve seeing the general practitioner personally. Most parents, however, acknowledged that they also consulted their general practitioner, at least occasionally, for familiar acute symptoms, and even those who looked primarily to the paediatric HIV team for medical care wanted to be in a position to do so should the need arise. The three families who lived outside London were more likely than the others to turn first to their general practitioner for help with acute symptoms.

Difficulty in distinguishing between "normal" and HIV related symptoms

It is funny like that. Even if she has got a little thing I have got to see to it and rush to the doctor. The doctor at the hospital says that she can be sick and it can be nothing to do with the HIV. But I worry none the less, even though he often says it has nothing to do with that.
(mother of 3 year old girl)

I panic more with her than we would with the other one. Because you know that you have got to catch it in the bud, otherwise it all could be too late. So we do worry, like where we would probably go to the doctors with her and they'd have said, "She'll be all right in the morning," we would have waited till morning. But with her we just keep phoning up and we are not satisfied to wait. Because if she does get anything, she does get ill very quickly. She really is pulled down.
(adoptive mother of 4 year old girl)

Constraints on greater involvement with general practitioners

Parents' accounts pointed to three main factors as constraining their use of general practice in caring for their HIV infected children. Firstly, even when children were apparently well and free from symptoms, parents were aware that their health was precarious and could deteriorate quickly. They often felt uncertain about how to distinguish between "normal" childhood symptoms and the effects of the underlying HIV infection or were anxious about how to stop such minor illnesses from developing into anything more serious. In this context, parents preferred to err on the side of caution and to go straight to the specialist paediatric HIV team when their child developed symptoms. This inclination to seek expert advice straight away was implicitly encouraged by the paediatric HIV team through their efforts to make their hospital service as accessible as possible to anxious parents. Whatever its intention, the consequence of open access was to reinforce among parents the notion that they should go straight to the hospital clinic when they became concerned about their child's health. This view was further reinforced by general practitioners themselves, who, like the parents, were often uncertain of the significance of symptoms and routinely referred children to hospital whatever the problem they presented with.

The second theme in the parents' accounts was their observation that general practitioners *themselves* did not feel competent to treat HIV infected children and thought it was more appropriate for children to be taken straight to the hospital when they became ill. In many cases, frequent visits to the hospital had given rise to a close relationship between the family and the paediatric HIV team, and this also acted to exclude the general practitioner from their care. Children themselves were particularly responsive to the sort of personal attention provided by the paediatric HIV team. For many families, the team had taken on the

Feelings about general practitioners' competence to treat HIV infected children

I don't bother to go to my GP. I just go to the hospital clinic straight, if she is very ill. When I go to the GPs, they just send me to the hospital clinic. . . . We don't go to the GP much. They do know, [the paediatric HIV team] told them. But if she was ill I would take her straight to him anyway. Anything that happens, I take her straight to the hospital clinic because everybody knows about her and how to care for her.

(mother of 3 year old girl)

I hardly use the GP at all. I just prefer to go to the hospital clinic. I can get help straight away. Because if I go there, they know the history and everything. If I go to the GP, it is so boring having to explain everything. There is always a pile of questions they need to ask.

(mother of 6 year old boy)

If she is ill, [she] won't go to the GP, she always wants me to call the [paediatric HIV team] doctor. We find it easier just to take her to [the team doctor]. When [she] is not well she prefers to see [the team doctor] because [the doctor] talks to her and I think [she] finds [the doctor] knows what she wants. She is much better if I go to [the team doctor] rather than calling the GP in.

(mother of 4 year old girl)

role of primary care providers and neither the parents nor the general practitioner saw any great benefit in complicating matters by involving the general practitioner as well.

The third constraining factor was the parents' concern about preserving confidentiality in a busy general practice. HIV is highly stigmatising, and parents feared that their children would suffer discrimination and rejection if their diagnosis became known. Some parents did not trust their practice to keep the diagnosis private, and indeed those who had changed general practitioner recounted how their previous doctors had disclosed it widely within the practice. Others pointed out that each time they attended their surgery, their notes were seen by various individuals, any one of whom could, intentionally or not, divulge their diagnosis. The greater the number of people locally who had access to the diagnosis, the greater the risk that it would become public. Parents thought they could limit this risk by limiting their contact with their general practitioner and going instead to the hospital clinic, which was geographically removed from their local community.

Discussion

The accounts of their relationship with general practice given by parents of HIV infected children were elicited in qualitative interviews over an extended period. The result is a detailed and contextualised picture of their experience, although the use of a qualitative approach has also meant that the study is based on only a relatively small number of families who attended just one London clinic.

While there was some variation among the families, overall this study shows that general practitioners have a relatively limited role in the care of children with HIV infection, largely in relation to the prescription of routine drugs. Virtually all parents regarded the paediatric HIV team as their primary source of medical care and, although many also had a good relationship with their general practitioner, most claimed that they "never go to the GP."

Why are parents reluctant to involve their general practitioner in the care of their HIV infected children?

Previous studies have pointed to patients' worries about maintaining confidentiality in general practice.[5 11–13] In this study, such concerns were closely related to fears that their diagnosis would become known to other people in their community and that they would become subject to stigma and discrimination. These may be particularly difficult anxieties to allay as they derive from the team approach and community involvement that are core features of primary care.

A second factor previously identified was the view that general practitioners lacked knowledge and experience of HIV infection and AIDS[11] and that hospital staff were more expert in dealing with the condition.[14–16] This view was also expressed by the families in this study, although they made it clear that their views derived from the attitudes of general practitioners, who routinely referred them to the hospital, and from the actions of the paediatric HIV team, who provided the kind of direct access and personal service more commonly associated with primary care.

A third factor commonly cited—fear of an unsympathetic response to the diagnosis [11–14]—was not reported by the families in this study. For a fifth of the families the diagnosis of HIV infection had created difficulties in their relationship and three had changed general practitioner as a result, but by the time of the study all the families were satisfied with their relationship with their general practitioner. This suggests that it may be relatively straightforward to

Anxiety about maintaining confidentiality in the surgery

I am just waiting for the receptionist or someone who is looking at his notes to say HIV. I am a bit scared because it is there on his notes. . . . I get a bit worried because there are people around waiting to see the doctor and I get scared in case somebody says HIV about us. She [the receptionist] hasn't yet said anything, she just reads the notes. You see if you are worried about something and you don't have an appointment you just come in to the desk and they get your notes out. I suppose things like that are nothing really but you don't know how people are going to take you.

(mother of 2 year old boy)

The last time I saw her [health visitor] at the health centre, I didn't really like the way she was talking to me about the HIV when everybody was listening. So I don't really want to go back there anymore.

(mother of 6 year old girl)

We are lucky we have got a good GP now. She knows. The first GP that referred us to hospital [not the study hospital], the hospital went and told him without us giving permission for it. Which was bloody wrong. And then he went around and told everyone else in the practice. So we left. We included that in the formal complaint against the specialist. . . .

(father of 5 year old girl)

overcome this constraint if efforts are made to match patients with sympathetic and supportive doctors.

A fourth factor, however, has not been reported in the literature before. Previous studies have distinguished between problems that are and are not related to HIV infection and have reported a much greater willingness among patients to consult the general practitioner for problems that they perceive as not related to HIV.[5] What is distinctive about the families in this study is the parents' accounts of how difficult or inappropriate it is to make such a distinction in relation to children with HIV infection. In the context of such parental uncertainty, it may be more difficult to identify a clear medical remit for the general practitioner.

What is the role of general practitioners?

This does not mean that there is no role for the general practitioner in the care of children with HIV infection. Parents valued their doctors not so much for their medical skill but for the emotional and practical support they provided. As the drug regimens children are prescribed become more complex and demanding to implement, general practitioners may be called on to provide more support of this kind. Any further development of the general practitioners' role, however, will need to build on existing local services and relationships with specialist providers and take account of parents' concerns about the greater involvement of general practitioners in the care of children with HIV infection.

Two further boxes—quality of relationship with general practitioner and use of primary care services—can be found in the electronic version of this paper on *BMJ*'s website.

Ms Jo Dodge helped with recruiting families and Ms Katy Pepper recruited families, carried out the interviews, and transcribed the tapes.

Contributors: MB and EB had the original idea for the study and analysed the data. MB designed the protocol, conducted the literature review, and wrote the paper. SW and DM contributed to the design and management of the study. All authors contributed to the final draft of the paper. MB is the guarantor.

Funding: The study was funded by a grant from the Department of Health.

Competing interests: None declared.

1 Singh S, Mansfield S, King M. Primary care and HIV infection in the 1990s. *Br J Gen Pract* 1993;43:182-3.
2 Smith S, Robinson J, Hollyer J, Bhatt R, Ash S, Shaunak S. Combining specialist and primary health care teams for HIV positive patients: retrospective and prospective studies. *BMJ* 1996; 312:416-20.
3 King M. London general practitioners' involvement with HIV infection. *J R Coll Gen Pract* 1989;39:280-4.
4 Madge S, Mocroft A, Olaitan A, Johnson M. Do women with HIV infection consult with their GPs? *Br J Gen Pract* 1998;48:1329-30.
5 Sheldon J, Murray E, Johnson A, Haines A. The involvement of general practitioners in the care of patients with human immundodeficiency virus infection: current practice and future implications. *Fam Pract* 1993;10:396-9.
6 Communicable Diseases Surveillance Centre. AIDS and HIV infection in the United Kingdom: monthly report. *Commun Dis Rep CDR Weekly* 1998;8:386.
7 Nicoll A, McGarrigle C, Brady A, Ades A, Tookey P, Duong T, et al. Epidemiology and detection of HIV-1 among pregnant women in the United Kingdom: results from national surveillance 1988-96. *BMJ* 1998;316:253-8.
8 Boulton M, Walters S, Miller D, Beck E. *The experience of families of children with HIV infection.* London: Department of Epidemiology and Public Health, Imperial College School of Medicine, 1997.
9 Fitzpatrick R, Boulton M. Qualitative methods for assessing health care. *Qual Health Care* 1994;3:107-13.
10 Beck E J, Griffith R, Mandalia S, Beecham J, Boulton M, Walters M, et al. *The hospital and community services study of families with HIV infection: use and cost of community service provision.* London: Department of Epidemiology and Public Health, Imperial College School of Medicine, 1997.
11 Mansfield S, Singh S. The general practitioner and human immunodeficiency virus infection: an insight into patients' attitudes. *J R Coll Gen Pract* 1989;39:104-5.
12 Clarke A. Barriers to general practitioners caring for patients with HIV/AIDS. *Fam Pract* 1993;10:8-13.
13 Shaw M, Tomlinson D, Higginson I. Survey of HIV patients' views on confidentiality and non-discrimination policies in general practice. *BMJ* 1996;312:1463-4.
14 King M. AIDS and the general practitioner: views of patients with HIV infection and AIDS. *BMJ* 1988;297:182-4.
15 Guthrie B, Barton S. HIV at the hospital/general practice interface: bridging the communication divide. *Int J STD AIDS* 1995;6:84-8.
16 Huby G, Porter M, Bury J. A matter of methods: perspectives on the role of the British general practitioner in the care of people with HIV/AIDS. *AIDS Care* 1998;10(suppl 1):583-8.

(Accepted 19 April 1999)

Key messages

- With appropriate help from the paediatric HIV team when necessary, all parents were willing to register with a local general practitioner and to disclose their child's HIV infection
- Parents remained oriented towards the specialist paediatric HIV team as their main source of medical care and looked to the general practitioner largely for routine prescriptions
- Parents preferred to go directly to the paediatric HIV team when their child developed new symptoms because of their own uncertainty about how to distinguish between "normal" childhood symptoms and those related to HIV infection
- Parents were reluctant to consult their general practitioner because they observed that he or she did not feel competent to treat HIV infected children and because they were concerned about the difficulties of maintaining confidentiality in a busy surgery