CENTRAL BIRMINGHAM HEALTH AUTHORITY

CONSEQUENCES OF AIDS TO HAEMOPHILIA SERVICES

The need for additional Resources within the Central Birmingham Health Authority

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We have been aware of the exposure of haemophiliac patients to the causative agent of the acquired immune deficiency syndrome (AIDS) for 2 years. It is now possible to begin to quantitate some of the long term effects of this exposure within the haemophiliac population and to define consequent changes required in terms of services and obligatory increases in expenditure. This paper has been prepared as a discussion document to enable officers within the Central Birmingham Health Authority to reach an agreement on how best to fund the changes in services that are required for patient care and staff safety.

The haemophiliac population within the West Midlands represents 11% of all the haemophiliacs in the United Kingdom. The majority (about 75%) are registered with the Queen Elizabeth Hospital or Birmingham Children's Hospital within the Central Birmingham Health Authority. At the Queen Elizabeth there are 423 patients registered as having a bleeding disorder but of these approximately 90 attend regularly for therapy or use Factor VIII concentrate at home. Of this population 56 are known to be positive for antibodies to HTLV III virus and have clearly been exposed to the causative agent of AIDS. Because some patients are continuing to become positive having been initially found to be negative all haemophiliacs are now considered to be high risk cases with regard to possible transmission of blood born disorders. This has particular implications with regard to laboratory and dental services.

Of the severe haemophiliacs registered at the Queen Elizabeth one patient has died of AIDS, another patient is under investigation as suspected of having AIDS and approximately 4 or 5 other patients are suffering from AIDS related syndromes (thrombocytopenia or hepatosplenomegaly). Of the sexual partners of haemophiliacs 25 have been tested to date and only one was found to be positive. None have shown any evidence of AIDS. It is hoped that no further cases of exposure to the causative agent will occur through Factor VIII concentrates since this is now heat treated but it is clear that the effect on those haemophiliacs already exposed to the virus is considerable and is likely to be long lasting. Clearly those patients who are positive for antibodies will need increased and more detailed follow-up and counselling. Duration of clinics and visits to the Haemophilia Unit on East 4B have increased significantly. Those haemophiliacs who were hoping to start or increase their family have been advised not to have children at the present time because of the risk of intra-uterine spread of the virus. This has caused very considerable anguish and increased counselling time. Young male haemophiliacs who are sexually active but unmarried have also required detailed and indepth counselling with regard to their future behaviour.

At the <u>Children's Hospital</u> there are 140 patients with bleeding disorders and of these there are 63 severe haemophiliacs requiring regular treatment. Approximately 60% of patients are HTLV III seropositive. Two boys have had pre AIDS since 1982 and a further 8 boys have persistant lymphadenopathy. Others have been documented with thrombocytopenia and all HTLV III seropositive patients have lymphopenia with selective depression of T4 subset lymphocytes. Unusual outbreaks of pulmonary tuberculosis (1981/2) and more recently hepatitis B in previously immune patients indicates that new and unexpected complications are arising in these children.

Parents and the children require counselling and reassurance frequently and a particular problem is the sexual counselling of sexually mature boys although they are under 16 years of age. Obviously this essential work is very time consuming and existing resources are already stretched and inadequate.

The problems that exist at present and are likely to continue for the next few years have so far not been recognised sufficiently at national or certainly at regional level. A report of the Regional Management Team regarding AIDS makes only scant mention of haemophilia and does not comment on the need for increased resources (enclosure 1). Because of this it has been felt necessary to approach the District Health Authority with regard to seeing what improvements can be made in the short term since staff and capital support requested under RCDRS has been deferred for beyond 5 years. The relevant areas will be considered under the following headings;-

(a) Factor VIII supplies.
(b) The need for an additional haemophilia sister.
(c) The need for support to the Dental Department.
(d) Revenue consequences of barrier nursing of patients with antibodies to HTLV III who are bleeding externally or require surgery.
(e) Laboratory safety.
(f) The need for additional social worker support or a counsellor. (This now realistically requires to be 2 full-time posts, one at the QEH and one at BCH)
(g) Requirement for carrier detection to reduce the future incidence of severe haemophilia in the population.
(h) Haemophilia SHO at Birmingham Children's Hospital.
(i) Bronchoscopy service at Queen Elizabeth Hospital.

(a) FACTOR VIII CONCENTRATE SUPPLIES

All Factor VIII concentrate is now heat treated and it is unlikely that a signficant number of haemophiliacs will in future become exposed to the HLTV III virus through this source. At present supplies of National Health Service Factor VIII concentrate have improved significantly over the last year and are running at 240 bottles (75,000 units) each month. Any short fall, which is considerable, is made up by the purchase of commercial Factor VIII under a Regional contract currently held by Armour Pharmaceuticals. It is hoped that in the next year to eighteen months the N.H.S will move nearer to self sufficiency although it is unlikely that full self sufficiency will be achieved. The present improvement in supplies of N.H.S Factor VIII concentrate may make it possible to divert money from the present commercial Factor VIII budget into other areas to provide an adequate service in the light of exposure of haemophiliacs to HTLV III.

(b) THE NEED FOR SECOND HAEMOPHILIA SISTER

This has been submitted under RCDRS to the Regional Health Authority but is unlikely to materialise for another 2 - 3 years. The full case for an additional haemophilia sister prepared by Dr Hill is attached as enclosure 2. The second page of this document shows that there has been a 4 fold rise in attendances to the Haemophilia Unit in the past 5 years with a doubling having occurred since the AIDS outbreak. The second haemophilia sister would work both at the Birmingham Children's Hospital and the Queen Elizabeth Hospital so that there would be 3 haemophilia sisters within the District and year round continuity of cover at each hospital could then be assured.

(c) DENTISTRY

The Dental Department at the Queen Elizabeth Hospital has for many years provided a specialist service for haemophilia patients. Because of the number of patients positive for HTLV III virus many haemophiliacs are having difficulty finding general dental practitioners prepared to care for their teeth. This has had the effect that the Dental Department at the Queen Elizabeth Hospital is now acting as general dental practitioner to approximately 120 haemophiliac patients. Because the risks of infection with HTLV III virus is very difficult to quantitate, all such patients are assumed to be at risk of passing on the infection and precautions similar to those for patients positive for hepatitis B surface antigen are taken. The increased cost to the Dental Department is quite considerable and there is an immediate need for approximately £7,000 to be spent on surgical and dental instruments. (see attached enclosure 3) Also as part of enclosure 3 is included the submission under RCDRS from the Dental Department which includes the requirement for a clinical assistant, a dental surgery aid and capital developments in terms of surgery accommodation and equipment. I understand that funding for this has been deferred to beyond 1991. There is clearly going to be an urgent need to bring this forward or provide funds within the District if this essential service is to continue. Mr Totten at the Birmingham Children's Hospital has been asked to consider the implications for the Children's Hospital and his submission will follow. In terms of attempting to minimise spread of HTLV III virus in the population provision of dental treatment within the hospitals of the Central District for all HTLV III seropositive patients is both sound and essential.

(d) BARRIER NURSING OF HAEMOPHILIACS WITH EXTERNAL BLEEDING WITHIN THE Q.E.H

In the past few months approximately one patient at any one time has been in the Queen Elizabeth and has required barrier nursing to protect staff from the possible risk of acquiring infection with the AIDS virus from haemophiliacs who are bleeding externally, e.g haematuria. The cost of this barrier nursing, assuming one patient at at time within the Queen Elizabeth Hospital is £2.83 per day in disposables plus 50 re-usable gowns per annum at £2.50 each = approximately £1,100 per annum. To this should be added the additional precautions now being taken routinely within the Haemophilia Unit which will bring the overall figure to approximately £1,500 per annum. There is a requirement for a small budget, say £150.00 per annum, for buying replacement items of equipment within the Haemophilia Unit on East 4B to maintain safety levels.

(e) LABORATORY SAFETY

All specimens from patients with registered bleeding disorders are now treated as if they were potentially infected with HTLV III virus. This has been accommodated with minimal increased revenue costs but the coagulation tests which are an essential adjunct to the management of these patients remain a cause for considerable concern. These tests are performed manually in open systems with a visual end point of a plasma clot and considerable advance in safety would be obtained if these tests could be performed automatically using a Labsystems FB 9, 10 coagulation analyser. This equipment was requested both for the Queen Elizabeth and Children Hospital under the RCDRS capital equipment application.

The cost of each machine is £13,547 as of January 1986. There will be no additional revenue consequences other than the maintenance contract for the machine at 10% capital costs per annum. (Enclosure 4)

(f) SOCIAL WORKER/COUNSELLOR

There is clearly a need for more indepth counselling and support for haemophiliacs within the whole of the West Midlands, additional to that being carried out by the consultant medical staff and haemophilia sisters within the Central District and other hospitals. This will be the subject of a subsequent paper to be prepared by Dr F G H Hill. (now attached as enclosure 6)

(g) CARRIER DETECTION

The case for extending carrier detection and antenatal diagnosis of haemophiliacs to early trimester techniques using DNA probes has already been made by Dr Hill. For information this is included as enclosure 5.

(h) SENIOR MEDICAL HOUSE OFFICER

Senior Medical House Officer for Haemophilia Unit at Birmingham Children's Hospital. (See separate appended case).

(i) BRONCHOSCOPY SERVICE

An additional bronchoscope (submersible) is needed at the Queen Elizabeth Hospital for suspected AIDS patients. (see appendix 7)

As consultants responsible for regional specialities at the QEH and BCH including haematology, quality control and bone marrow transplantation, we are well aware of the pressures on RCDRS monies. However the effect of AIDS/HTLV III on the haemophiliac population appears to have been rather overlooked in the stampede to provide emotional support to the homosexuals. Haemophiliacs have been inadvertantly infected by the virus as a by product of their therapy. The impact and scope of this problem is a new occurrence and could not have been foreseen in the overall concept of expansion of medical services and the idea of a 5 year roll forward funding scheme simply is inappropriate for this sort of problem. Aspects regarding the safety of laboratory, dental and other hospital personnel would seem to need very high priority and of course many improvements have been made as a result of the Howie report. There is an urgent need both for new money to be found within the West Midlands Regional Health Authority to deal with the AIDS/HLTV III problem amongst haemophiliacs (some of this perhaps could be provided on a non-recurring basis until recurring monies become available) and there is also a need for some re-distribution of money within the Haemophilia service in the Central District. It should be possible to maintain a safe and acceptable level of service for these patients and a combination of the 2 above without jeopardising other equally needy projects.

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SUMMARY OF REQUEST

a) Factor VIII; additional costs due to heat treatment already dealt with.
Rationalisation of supplies/funding needed.

			£
b)	Haemophilia Sister		10,000
c)	Dentistry (QEH); needed now	- Pay	6,000
		Non-pay	8,000
		- Needed 1990; Pay	16,000
		Non-pay	10,000
		Capital	40,000
d)	Barrier nursing (QEH)		1,500
e)	Laboratory safety (QEH and BCH)		
		- automated equipment (£13,000 each hospital)	27,000
		- revenue	3,000
f)	Social workers (one for each hospital)		20,000
i)	Bronchoscope (QEH)		7,000

Additional bids for the Children's Hospital in respect of ante-natal diagnosis and an SHO have been submitted via other channels.