

PE Exhibit 2

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Counselling HIV positive haemophilic men who wish to have children

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All citizens of the United Kingdom, including people with HIV and AIDS, are awarded rights under international law which the United Kingdom government has agreed to uphold. Among these rights, which exist in international treaties,¹ are the right to marry, the right to found a family, and the right to education.

Many haemophilic men were infected with HIV as a result of the administration of clotting factor concentrates before it was known that they were contaminated with HIV. A proportion of these were adolescent or young men who then, or later, had stable relationships and wished to have children.

Present series

It is the practice at the Royal Free Hospital's haemophilia centre to review severely affected haemophilic patients (factor VIII concentration <20 U/l) on a six monthly basis and mildly affected patients (factor VIII concentration >20 U/l) annually. Patients are asked to bring wives or sexual partners and family members to reviews so that the effects of haemophilia on the family can be addressed. A cohort of 111 HIV positive haemophilic patients has been followed up since the first seroconversion in October 1979 to August 1991^{2,3} and, when possible, their partners and families have been seen at regular intervals.

Before HIV testing was available, between 1983 and 1984, information was provided about the likely modes of transmission of HIV and the inability at that time to diagnose those infected. Safer sexual practices, as described in "Haemofact Bulletin," were advocated.⁴ When HIV testing became available in early 1985 all haemophilic patients were invited to bring their sexual partners for counselling and HIV testing. Partners were interviewed separately and asked to answer confidential questions about their sexual practices.

By using confidential questionnaires to determine attitudes to childbearing 26 couples in stable relationships have been closely followed up, 24 since 1985 and two since 1987. Partners and children of HIV positive haemophilic patients have also been tested annually for HIV serology and CD4 lymphocyte count.

Counselling

The counselling technique used is based on that of the Milan associates.⁵ Questioning is used to engage the family and involve them in giving thought to their situation as well as revealing the views and attitudes of other family members. Exploring people's beliefs, wishes, and the extent of their knowledge of HIV enables them to make informed decisions. Sequential questions facilitate the discussion of difficult issues, while hypothetical, future oriented questions help the couple to understand some of the long term implica-

tions of having a child. Examples of questions used to help people when they are considering whether to have a child are:

- (1) What has made you decide that this is the right time to have a child?
- (2) If you decided not to have children how would that affect you/your relationship?
- (3) Which of you most wants to have a child?
- (4) Is there anything about your family or your community which puts pressure on you to have children?

Questions are used not only to elicit information about the family but also to assist in imparting information by assessing the extent of the family's knowledge. In this way misconceptions can be corrected and gaps filled while members are actively engaged in thinking about the subject under consideration, rather than being flooded with information which they may not understand or be ready to accept. Questions can also be used to check the extent of their grasp of the information offered. For example, "If your sister/brother/girlfriend were to ask you to explain this what would you tell them?" and "How do you think that HIV is most often transmitted?"

If it was established that a couple did wish to have children they were asked to consider the following possible scenarios.

- (1) The partner of an HIV positive haemophilic patient could remain HIV negative and have an uninfected child. The haemophilic partner might die earlier from progression of HIV disease than would normally be expected but the mother would have a child which she might otherwise not have had.
- (2) The mother might become infected with HIV but the child could be uninfected and possibly become an orphan.
- (3) Both mother and child could become infected with HIV, resulting in all three family members being infected.
- (4) The woman could have artificial insemination with frozen semen from a screened donor so that she could experience having a child which she and her partner could share without the risk of HIV infection. If the child was a girl she would not be a carrier of haemophilia.

For those who felt that they wished to take one of these risks and proceed to have a child it was advised that they should practise safer sex—for example, using condoms at all times except at ovulation. The use of ovulation kits was recommended (and these have been provided at the Royal Free Hospital since 1988) to reduce the risk while attempting to achieve pregnancy. HIV testing of the mother was offered at three months' gestation if the couple had indicated that they would prefer to terminate the pregnancy in the event of her seroconversion. Provided the mother remained HIV negative and continued to use safe sexual practices

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breast feeding of the infant was encouraged. The physical and cognitive development of the infants was assessed soon after birth and at yearly intervals.

Outcome

When counselled in 1985, 14 of the 26 couples decided not to have children. Of these, four couples already had children conceived before the fathers became HIV positive and had not planned to have more. Nine couples decided not to have children because they feared transmission of HIV to the wife and possibly to the child; their decisions had remained unchanged up to 1991. The remaining couple thought that they were not ready to have children in 1985 for financial and personal reasons separate from considerations related to HIV. Towards the end of 1990 they decided that they would like to have a child while the husband remained asymptomatic. They were provided with an ovulation kit but after six months' failure to conceive requested referral to a fertility clinic. The wife remained HIV negative.

Twelve couples had 14 children conceived after the father had been infected with HIV. Five couples had conceived before the HIV test became available and thus before the father's seropositivity was known. One of these five chose to have a second child after the husband's diagnosis was established. One couple decided to have a second child but, having failed to conceive after three months using an ovulation kit, were overcome with anxiety about transmission of HIV and abandoned any further attempts at pregnancy. One couple had an arranged marriage and haemophilia had not been disclosed. Their first child was born in January 1985 and the mother was pregnant with their second child when they were referred for counselling in 1987. The mother was found to be HIV positive and chose to have the pregnancy terminated: it is not known when she seroconverted. The haemophilic husband progressed to AIDS and they arranged for the wife's brother to care for their child if she should become ill. Of these five couples, one of the husbands died of AIDS, two contracted AIDS, and three remained asymptomatic.

The brother of the man with the arranged marriage similarly had an arranged marriage in which neither haemophilia nor HIV infection was disclosed. The wife learnt of the diagnosis during the last month of her pregnancy in 1987, after which they were referred to the Royal Free for counselling. They subsequently had a second child delivered in July 1991 after a great

deal of discussion and pressure from the wife to have another child. Mother and child remained HIV negative.

Five couples made a considered decision to have their first child knowing of the husband's seropositivity and the risks. All the wives and children were HIV negative. One of these fathers died of AIDS, the others remained asymptomatic.

One couple had an unplanned pregnancy. Although the father was known to have been HIV positive since 1979² on retrospective testing, he was well and they decided to continue the pregnancy. Mother and child remained HIV negative.

All 14 children were HIV negative and were growing and developing normally. One of the wives was seropositive but the time and route of infection were unknown. None of the couples seemed to regret having had children.

Conclusion

It is clear that some people choose to have children in spite of their risk of HIV infection, and young couples such as those described will continue to present. Life has many risks, some of which can be avoided. It is for each individual to decide what degree of risk he or she finds acceptable, but when others are involved in the consequences of risk taking dialogue between the parties is essential. The role of the counsellor with couples where one partner is HIV positive and one or both wish to have children is to facilitate discussion and ensure that both are in possession of all the available information. Finally, they should be assisted in reducing the risk as far as possible while being allowed the basic right to exercise their own choice.

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ANY QUESTIONS

What are the arguments for weighing the placenta?

In most delivery suites where facilities are available the weight of the placenta is recorded together with that of the newborn baby, and standard obstetric teaching describes the normal crude placental weight as being one sixth the weight of the fetus. Large deviations from this rule of thumb may alert medical staff to important disease, as in the large placenta of fetuses with congenital syphilis, a disease that is still an important cause of perinatal mortality worldwide and yet can be treated.

Ratios of placental weight to birth weight vary so widely that interpretation of individual measurements is of limited value. But large population studies of even crudely measured weights have shown interesting differences in the ratio of placental weight to birth weight with respect to such variables as the baby's sex, maternal parity, and gestation.¹ Similarly, relative placental weights differ from those of normal populations in maternal conditions known to have a deleterious effect on perinatal outcome

such as high maternal haemoglobin concentrations and hypertension.² Recent epidemiological evidence has emerged relating adult disease to intrauterine antecedents: the incidence of hypertension was increased in adults who had been small babies with higher placental weights.³

Such observations may provide the direction for research into the nature of control of intrauterine growth and the role of the placenta and would justify continued weighing and possibly even more accurate measurement by standardising placental preparation by draining the organ of blood and trimming the membranes and cord before weighing it. Data retrieval and analysis should be facilitated by increased use of computerised obstetric records.

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