

IN CONFIDENCE

EXPERT ADVISORY GROUP ON AIDS

Note of a meeting of the sub-group on AIDS Counselling held on Wednesday 13 February 1985 in room 108 Russell Square.

Present: In chair - Dr M E Abrams (DHSS)

DHSS

Professor M Adler

Dr J Green

Miss D Jenner

Dr A J Pinching

Professor A J Zuckerman

Dr M Sibellas

Dr D Holt

Mr D M Bailey

Apologies for absence were received from Professor Geddes, Dr Gunson and Dr Pereira-Gray. Dr Abrams thanked Dr Green for agreeing to join the sub-group.

Introduction

1. The Group took as a basis for discussion the draft paper "AIDS Counselling" prepared by the Department.

Sources of Patients/Individuals Needing Advice

2. It was agreed that the list at paragraph 4 of the draft paper should be extended to include voluntary staff and health care personnel (this should cover all health care staff, including dental practitioners, whether working in hospitals or in the community; drug addicts; acupuncturists; and tatooists).

Counselling: where, when and by whom

3. It was recognised that the Blood Transfusion Service (BTS) was working under intense pressure and was not in a position to counsel every individual found to have a positive blood test. The service generally had no premises of its own, and blood testing was carried out in a variety of places such as school halls etc which were totally unsuitable for counselling.

4. Departments of Genito Urinary Medicine were seen as more appropriate places for AIDS counselling - though there would be certain individuals for whom this was not suitable. Professor Adler stressed that the reference in paragraph 5(ii) of the draft paper to "full back-up facilities" gave a somewhat false impression, and he added that the present staffing levels in GUM clinics would certainly not be sufficient to cope with the workload to be expected if they took on the main role in AIDS counselling. Dr Pinching supported this view, adding that the demands would be far greater for GUM clinics than for the BTS. It was concluded that GUM clinics should, at least, provide counselling facilities for those discovered to be positive through tests carried out on their premises - though it was recognised that even this would require additional recourses.

5. With regard to hospital consultants, the Group agreed that provided there was one consultant, of sufficient seniority, in each district, nominated to take the lead on counselling, it was to some extent irrelevant which consultant it should be. This should be a matter for local (ie District) decision, though the DHSS had a responsibility to ensure that the decision was taken, and appropriate arrangements made.

6. It was agreed that general practitioners could not in the early stages be expected to provide a full counselling service for AIDS patients (or those individuals found to be sero-positive) but should be sufficiently informed on the subject to know to whom a particular individual ought to be referred. Persons found to be sero-positive by the BTS should be referred, in the first instance, to their gp unless they indicate that they wish otherwise. AIDS is a sexually transmitted disease and it is not possible to make assumptions as to what individuals would want their gp to know. Care should also be taken in the wording of the referral letter; it should say no more than that the test had revealed an abnormality in the blood, and that the gp should be consulted.

7. Professor Adler pointed out that in the final analysis, patients are free agents and there could be no compulsion in referring them to any one particular source for counselling. It would be more satisfactory if they could be given a choice, ie their own gp, a GUM clinic, hospital consultant etc. There was however an onus on the person (or service) discovering the positive test result to ensure that they were referred somewhere.

Education

8. Professor Zuckerman felt that the most urgent action needed was to educate health care professionals. Professor Adler said that health districts should be advised to develop their own facilities for counselling AIDS patients, and that a small handful of London hospitals (eg St Mary's, The Middlesex, St Stephens) could not be expected to cope indefinitely.

9. One line of approach to this problem might be through the Royal Colleges - though it was recognised that this would not cover some very important groups such as Laboratory workers.

Dissemination of Departmental Advice

10. The Group considered the respective merits of various methods of distributing Departmental advice on counselling. It was suggested that a CMO letter, or any "official-looking" document could remain unread. A colourful, carefully-designed, leaflet would be more likely to achieve its objectives. All health care workers should be covered, though a slightly amended version might be necessary for different disciplines.

11. Dr Sibellas agreed to send to Dr Pinching copies of 2 American leaflets which were considered to be fairly good, and Dr Pinching undertook to prepare a draft for use in the United Kingdom, based on this American counterpart, for consideration at the next meeting of the sub-group (4 March). He would send a draft to Mr Bailey by 22 February.

12. Professor Zuckerman suggested that in addition to the leaflet, papers could be published in professional journals such as the BMJ, Lancet, the Nursing and Dental professional publications, and ASTMS magazines. This was agreed.

Training

13. The Group recognised that apart from deciding who should provide AIDS counselling, the question also arose, who should train these counsellors? AIDS counsellors would require, first and foremost, general health-care skills. If they also possessed counselling skills, so much the better. Knowledge of AIDS was perhaps the least important factor as this could most easily be provided through some form of training facility.

14. At present, only St Marys Hospital, Paddington was providing advice on a substantial scale. It was felt that other centres such as The Middlesex and St Stephens might be suitably equipped to help once they had received some basic training in this field themselves. Clinical psychologists were well-placed to take the leading role in this, but Dr Green stressed the general shortage of psychologists and it was agreed that where this proved impracticable alternatives would need to be found.

15. Miss Jenner stressed the vital importance of training nurses. Alone amongst the health-care professionals, nurses had a 24-hour a day contact with patients, and it was to them that individual patients often turned for help and advice.

16. Those doctors actually called upon to treat AIDS patients formed a most important groups requiring help/support/advice. The strain imposed upon them by their work could not be over-emphasised.

17. Dr Sibellas suggested that once some form of training facility had been established, a sensible way forward would be to call in for training those consultants in each district who had been nominated to be responsible for AIDS counselling (para 5). They would then be responsible for training within their district.

18. Dr Green agreed to provide (to Mr Bailey by 22 February) a paper setting out proposals for the establishment of some form of training facility for AIDS counselling.

The Nature of Counselling

19. The Group agreed with Dr Pinching that a number of "myths" eg the risk in using cups or sharing a room or toilet seat with homosexuals, needed to be exploded. Professor Zuckerman sounded a note of caution in that he felt the Department's statements should not be too categorical. For example, in referring to transmission of the disease it should use phrases such as "There is no evidence that AIDS is spread by" or "No cases have been documented of".

20. Referring to question 4. of page 5. of the Department's draft paper, the Group agreed that because of data protection legislation, only those people whom the patient agrees can be informed should be told of a sero-positive result. And in response to question 5. it was agreed that the most important advice for contacts and friends was to observe the basic rules of hygiene.

21. Professor Zuckerman agreed to produce a paper (again, by 22 February) on the nature of counselling.

Next Meeting of Counselling Sub-Group

22. 10 30 am on Monday 4 March 1985 in room 108, Russell Square.