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## 1. INTRODUCTION

It is a considerable oversimplification to analyse the costs of AIDS to the NHS in terms of the relationship,

Cost of AIDS = Number of AIDS cases X Cost per case.

Nevertheless this equation helps at least to begin to think about the issue.

## 2. NUMBER OF AIDS CASES

### a) What is an AIDS case?

The conventional CDC definition of an AIDS case derives from the period before the introduction of tests for identifying antibodies to the virus. Patients presenting with conditions indicating severe immuno-deficiency, such as Kaposi's sarcoma, pneumocystis carinii pneumonia and other very unusual 'opportunistic' infections were classified as having AIDS. The list of these infections is now recognised as a very long one (Bingham, 1985; Richards, 1985)

As more became known about the disease it was realised that in some respects the narrow definition of the disease in terms of a number of these opportunistic infections might be too restrictive because the virus may also cause direct damage. Many patients, though not apparently the majority, displayed the symptoms of the AIDS related complex (ARC) immediately after infection. This can involve swollen lymph glands, fevers, sweats, headaches, sore throats and skin conditions.

In addition to this those infected by the virus can display other symptoms indicating damage caused by the virus without developing 'real' AIDS. These can be persistent generalised lymphadenopathy, lung damage, brain damage, muscular weakness and liver damage. It seems quite possible that the virus is capable of directly affecting most parts of the body.

It should also be mentioned that many of the conditions now classed as opportunistic in an AIDS case are not the unusual conditions of the first patients classified as having AIDS. For example, on Bingham's list of opportunistic infections there is cytomegalovirus, herpes simplex, and the Epstein-Barr virus. It can therefore become something of a problem to define just what is an AIDS case. Should the cost of AIDS include all illness suffered by a person infected with the virus once he or she is diagnosed seropositive? At the other extreme should we only take classic AIDS into account?

Equally confusing is the current state of knowledge on the prognosis of those infected by the virus. For example Bingham gives the conventional model of infection causing ARC in a minority of those infected, and with only about 10% of those infected succumbing to AIDS after perhaps 2 or 3 years, while the remainder are asymptomatic.

This view does not go unchallenged. Occasionally the concern is voiced in extreme terms, as when Roger Scruton suggests that humanity may be wiped out by AIDS in 20 years unless a cure is found. At the same time there is a perfectly respectable case for the view that the situation is far more serious than the conventional position outlined by Bingham. For example, Jeffrey Lawrence of Cornell, writing in the December, 1985 Scientific American: 'By one estimate, which is probably conservative, 7 percent of the currently infected but still healthy individuals will develop AIDS each year.' The Lawrence view implies that, of 100 people infected, assuming that none will get full AIDS in the first two years, 20 will have, or have had, AIDS in 5 years, 44 in 10 years, 61 in 15 years and 81 in 25 years. The 7 percent figure may be the reverse of conservative, but a full AIDS percentage of only 10 percent seems a little optimistic, to say the least.

b) Future numbers of AIDS cases

Most estimates of future AIDS case numbers have been derived by projecting statistics of persons with the full AIDS. One common method is to project on the basis of simple geometrical ratios. For example it was observed in the US until about the beginning of 1983 that total AIDS cases recorded doubled about every 6 months. The 6 month geometrical ratio formed the basis of some early projections, but more recently the number of months required for cases to double seems to have increased to over 10 months. Present US total cases recorded are now in excess of 16,000.

In the UK cases seem to be doubling about every 8 months or so at present; at the end of October 1985 241 cases had been recorded. McEvoy and Tillett have used a simple log-linear relationship to project UK cases to 1988.

Another method is proposed by Mortimer. This again has the virtue of a certain simplicity, because it uses the US case numbers divided by 4.06 and lagged by 3 years. Both Mortimer and McEvoy and Tillett obtain practically the same number, about 1800 for new cases in 1988, but Mortimer's estimates for the intervening years are substantially higher than those of McEvoy and Tillett.

Curren et al (1985) project US case incidence using a more sophisticated polynomial model. The model indicates that 'approximately 12,500 new AIDS cases will be diagnosed between 1 July 1985 and 30th June 1986 with a 95 percent prediction interval ranging from 10,000 to 14,000.' The confidence intervals rapidly become very wide, so the model is apparently not too suitable for projecting too far into the future. Indeed such is the degree of uncertainty surrounding the question that it is doubtful whether any method can be regarded as very reliable beyond a year or two, unless quite wide confidence intervals are introduced.

Note that such projections are entirely concerned with full AIDS cases, and not with ARC cases or with other illness caused by the AIDS virus.

It is quite possible that US statistics are underestimating the numbers with full AIDS because many people involved have a strong interest in covering cases up. Patients themselves may not wish to inform those around them that they have AIDS; their families will be similarly inclined after they learn the truth themselves. The medical authorities may not wish to diagnose AIDS to avoid panic, and if cases can be treated at home without an AIDS label attached most hospitals, especially the private ones would probably welcome it. Full AIDS is probably invariably fatal so why cause more trouble than strictly necessary? The CDC definition of an AIDS case in terms of opportunistic infection invites the possibility of a non AIDS diagnosis. Against all this, however, the doctor who misdiagnoses a case in the US could invite legal action from anyone in contact with the patient who was later found to be infected with the virus.

c) Numbers who are Seropositive

Since the availability of tests for detecting antibodies to the HTLV3/LAV virus interest has begun to shift towards estimates of the numbers of people infected by the virus, or more accurately are seropositive. The first estimates of total numbers who are seropositive have been derived from the numbers of full AIDS cases, and from information provided by the San Francisco CDC cohort study, which gives information on the ratio of seropositives to full AIDS cases. It is this information that has provided the basis of estimates made last year of UK seropositives of 10,000 to 15,000. These were based on the estimated seropositive/AIDS case ratio for 1982 of about 77. Multiplying this ratio by 241, the total recorded number of cases in the UK, we may obtain an estimate of the number of UK seropositives of about 18,500 in October 1985.

The method lacks, however, a certain dynamic realism. For example we may project a total number of recorded cases of full AIDS in the UK <sup>in Oct. 1986</sup> assuming that cases are doubling every 8 months. The figure obtained, 682, can then be multiplied with the San Francisco seropositive/AIDS ratio for 1983 of 47 giving <sup>only</sup> an estimated 32,000 seropositive in the UK at that date. The problem is that by 1983 a majority of the San Francisco cohort was estimated to be seropositive, so the scope for a rise in the number of seropositives in the cohort was diminishing as the cohort approached seropositive saturation. This, coupled with a rather doubtful-looking method for estimating the seropositive numbers between 1981 and 1983, makes such estimates, if not worthless, at least very suspect.

In spite of such reservations it is of great importance to obtain accurate estimates of the numbers of the population who are seropositive. I confess, however, that I cannot think of an economical way to obtain this information. Perhaps if the DHSS offered a random sample of the population large financial incentives to have a blood test such estimates might be made, though at present the sample would need to be unrealistically large.

#### d) The At-Risk Groups

The at-risk groups are well-known - male homosexuals, intravenous drug users, haemophiliacs and perhaps blood transfusion recipients; though risks to the two latter categories have been reduced very considerably as a result of blood heating and screening. A further at-risk category is the spouses of infected persons, and children of parents with AIDS, especially if the mother has AIDS while pregnant.

With the exception of Haemophiliacs (I believe that there are about 4,000 in the UK) we are in a state of considerable ignorance about the actual size of these groups. It might be possible to add questions to one of the national surveys on whether people have received blood in the last two years. It may also be possible to get the information from the NHTS.

Estimates of the size of the practising male homosexual community have become confused in a miasma of sensationalism and propaganda. I believe Kinsey estimated the number at one in ten of adult males, but his classificatory criteria are to say the very least suspect. Homosexual groups probably play up the estimated numbers to enlarge their sense of importance and power. A confidential random sample of the male population might provide estimates with a degree of reliability, but I doubt it. In the US never-married males are sometimes used as a sort of semi-proxy for homosexual, but this may over-estimate the opportunities for and the attractiveness of marriage for the heterosexual male.

It certainly seems likely that male homosexuality has increased over the last 25 years since of publication of the Wolfenden Report and the legalisation of male homosexuality. But how reliable estimates of the actual numbers of at-risk homosexuals could be made is a considerable problem.

Intravenous drug users are another category whose size is not known. My impression is that the problem is surprisingly large and probably growing. The officers of a parents' group in High Wycombe estimated that the numbers there were several hundred, though they refused to attempt a more precise estimate. Neither can we be sure of the population base from which the several hundred are drawn, but it is probably in the region of 100,000. If the actual number of such users were 500, and this were the pattern over the whole country, then we should have perhaps 300,000 in the UK.



e) Numbers of AIDS cases -Information

It would seem that we do lack much basic information about the disease itself, especially about ARC and other non- full AIDS cases: we know little about the numbers of seropositives: and we know little about the size of the at-risk groups. Such information will be needed if we are going to make realistic estimates of the future scale of the AIDS problem.

One idea that I modestly propose for discussion is that perhaps one NHS region is selected to try to monitor the growth of the disease. Perhaps a study something along the lines of Acheson's Oxford Record Linkage Study might be possible.

3. THE COST PER AIDS CASE

As there is considerable doubt about the character of the diseases caused by the AIDS virus, and the likely prevalence of disease, it may be doubly difficult to make estimates of the cost per case. In addition very little has so far been written about the cost of AIDS.

a) The Cost of Full AIDS Cases

The CDC have estimated the medical costs of full AIDS cases in the US at between \$100,000 and \$150,000. I have written to ask for the basis of these estimates.

In the UK NUPE have estimated that the nursing cost alone of a full AIDS case is £20,000 (NUPE, 1985). This estimate may have been used as the basis for estimates of the cost of the full AIDS case itself (eg Meacher, 1985). In addition drug costs at St Mary's Hospital are given by NUPE at £110 per day for inpatients and £15 for outpatients. Annie Johnson at the Middlesex Hospital has made some estimates of the costs of full AIDS cases, but I have not yet seen these.

It would seem that considerable work needs to be done on the likely cost of AIDS to the NHS. The most immediate problem is the likely cost of treating these full AIDS patients.

One can anticipate certain difficulties at the onset. As long as these patients can be treated within existing facilities costs will be considerably lower than they would be if new units had to be opened. On the other hand existing treatment, particularly that at the teaching hospitals probably has a 'research' element that increases costs above 'routine' levels. It may be that the current AIDS patients are being given more treatment than the typical patient in the future.

Another problem is the degree to which AIDS cases should be regarded as quarantine cases. Most doctors responsible for the patient management of AIDS cases do not regard them as particularly infectious as long as extreme care is taken with blood samples and spills. Whether the general public can be persuaded to take this view is another matter. The degree of isolation required for AIDS patients will affect the cost of treatment considerably.

b) Outpatient Costs

Outpatient treatment for AIDS may prove to be far more costly than previously thought. All seropositives will have to be closely monitored (see the attached paper from the Wandsworth Health Authority); this will probably prove very costly. In addition there is already considerable demand for diagnostic tests, and this is expected to increase. There will be a need for more counsellors for helping people in distress and for contact tracing.

c) Costs of AIDS to Other Parts of the NHS

The effect of AIDS on other parts of the NHS is a great unknown. It is clear that AIDS will affect the mental health services (Ho et al, 1985; Fox and Cottler-Fox, 1986), and on the neurological services (Carne et al, 1985). Other inpatient services will almost certainly also be seriously affected.

The general practitioner service will also come into contact with AIDS related conditions (Bingham, 1985). At particular risk are dentists because they often draw blood. Even opticians may be affected because the virus has been found in tears (Fujikawa, 1985), though if such fluids do prove to be dangerous the management of AIDS patients will be far more complex than is now thought.

Explicit mention should also be made of the additional costs that are likely to be incurred by the Pathology services.

Malcolm Rees  
St James' Hospital,  
Balham.

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