

AIDS and the Rise of the Patient? Activist Organisation and HIV/AIDS in the UK in the 1980s and 1990s

Virginia Berridge

Zusammenfassung

AIDS und der »Aufstieg des Patienten«? Selbsthilfeorganisationen und HIV bzw. AIDS in Großbritannien in den 1980er und 1990er Jahren

Der »Aufstieg des Patienten« ist zum Thema der medizinischen und der historischen Literatur geworden. Sowohl in der neueren Medizingeschichtsschreibung als auch in der Gesundheitspolitik zeige sich – so wird behauptet – daß HIV bzw. AIDS den Einfluß der Patienten gestärkt habe. Der folgende Artikel untersucht diesen Sachverhalt anhand der Diskussion über Rolle und Einfluß von AIDS-Organisationen, weniger anhand von Überlegungen zu Veränderungen in der individuellen Arzt-Patient-Beziehung. Viele der publizierten Arbeiten zu HIV bzw. AIDS und deren Einfluß haben das Beispiel homosexueller Männer zu Grunde gelegt und die Erfahrungen der Organisationen von Drogenkonsumenten und Blutern ignoriert. Dabei ergibt sich, wenn man die letztgenannten Organisationen mit heranzieht, ein anderes Bild. Doch selbst unter den homosexuellen Männern kann das Bild von der »Patientenmacht« nicht so ohne weiteres aufrechterhalten werden. HIV bzw. AIDS führten zu einer zunehmenden »Medikalisierung« der Selbsthilfeorganisationen und waren der Vorreiter einer Entwicklung, die wieder stärker auf die öffentliche Gesundheit fokussiert war. Dazu kamen allgemeinere Veränderungen in den Beziehungen zwischen dem freiwilligen Sektor und dem Staat.

Introduction

The 'rise of the patient' has been a significant feature of the last thirty years of health policy and of the writing of health history.¹ Historians have increasingly tried to reconstruct the patient's rather than the consultant's view and there is much valuable historiography on the patient in history. Sociologists have argued that the consumerist view of health and the redefinition of the patient as consumer had its roots in the 1970s.² But there is less on the recent, or 'contemporary history' of these developments, and very little historical research on another aspect of recent patient history, the rise of patient organisations. The rise of health voluntarism in general since the 1970s largely remains to be studied. It is self organisation in this sense in the UK which is the focus of this paper. These health groups have taken various forms in Britain, some, like MIND, the mental health organisation, or the Patients' Association, have lobbied for improvements in service provision and for patients' rights. Others, like ASH (Action on Smoking and Health), founded in 1971, or the Coronary Prevention Group (CPG), founded in the late 1970s, were set up as 'single issue' policy pressure groups aiming to improve health through changes in policy rather than

1 Berridge (1999).

2 Stacey (1988).

specifically advocating patients' rights.³ A widening range of self help groups has testified to the rising popularity of alternative medicine and non medical routes to health care.⁴ These were essentially 'inward looking' groups aiming to improve individual health. In the 1990s, the 'rise of the patient' moved more centrally into UK government policy making. The patient was redefined as the consumer of health services and a plethora of initiatives – the Patients' Charter, needs assessment among them – testified to the increased attention to the people who were at the receiving end of services. These later developments have been much discussed by health policy analysts and others, but in some senses marked another outgrowth of the drive for patient power which began in the 1960s and 1970s.

In recent history, perhaps the clearest manifestation of the 'rise of the patient or consumer' has been ascribed to the response to AIDS in the 1980s and 1990s. Epstein's 'Impure Science' argues that US gay activists did shift opinion about trial protocols, management and recruitment, in ways that had a lasting effect. Gay activism brought problems in its train – who exactly did activists represent? But there was no doubting that 'patient power' won through.⁵ The purpose of this paper is to subject that view of HIV/AIDS to critical scrutiny. Was AIDS indeed an apogee of patient power in terms of self organisation? What did that patient power consist of? What does it tell us about the wider issue of the organisation of the patient's voice? I will argue, that, even for gay men, where the arguments for an optimistic view of the impact of HIV/AIDS are strongest, the conclusions about patient power should be equivocal. I will also argue that there has been a general failure to consider other groups with traditions of self organisation who were affected by the syndrome; here I will consider the role of haemophiliacs and of drug users. There is a broader overall context to this discussion; the nature of the relationship between voluntarism and the state and the change in that relationship which has taken place in Britain since the 1970s. The 'moving frontier' of the voluntary/statutory relationship has changed to accommodate a greater role for voluntary provision as a surrogate for state services. State funding of the voluntary sector has brought fears of the 'end of the voluntary sector' and its incorporation in the state.⁶

Gay men

The story of gay men and AIDS seems at first sight, to offer the clearest expression of the rise of patient power. In the UK, this could be seen through three strands of activity; the influence exerted by gay men in self

3 Berridge, forthcoming 2003.

4 Webster (2001).

5 Epstein (1996).

6 Whelan (1999).

help organisations on central government policy making; the impact of such organisations on treatment and trials; and the involvement of gay organisations in the rise of new forms of service provision and of alternative therapies.

AIDS organisations grew out of two earlier tendencies: the doctor/patient revolution of the 1960s and 1970s; and the decade of organisation building round gay health issues in the 1970s. For the 'gay community', AIDS intersected with the 1960s and 1970s agenda of gay liberation and the 'demedicalisation' of gay sexuality, and the growing importance of health issues for gay men in the 1970s and 1980s. The defeat of the disease model of male homosexuality had, ironically, been paralleled by the rise of health as a matter of concern in gay groups and as a specific concern of self helping organisations. In the UK, organisations like Switchboard and Gay Friend had developed a clear health dimension to their advisory and counselling activities. Self help groups, such as Group B for gay carriers of the hepatitis B virus, had come into existence; and gay men were increasingly using specialist GUM (genito-urinary medicine) clinics rather than general practice for non judgmental primary health care, informed by informal networks of information and advice about which clinics offered the best service. The response to AIDS thus fitted into pre-existing gay medical and health paradigms, drawing on gay 'consumerism' in health. The concerns for self help, for lay knowledge, and patient input were clearly important as formative influences for the generation to be subsequently most affected by AIDS.

The policy influence of gay men in the UK was significant. Elsewhere, I have identified three phases of the overall policy response; one of 'unambiguous voluntarism' from the early 1980s to 1986; a phase of national coordination and war time response in 1986-1987 and then one of 'bureaucratisation and normalisation' in the late 1980s and early 1990s.⁷ AIDS presented in a policy and scientific vacuum and early reactions to the threat it posed had a voluntarist and self helping ethos. The atmosphere of 'pure self help' comes over clearly from memories of that time. An early attender at meetings of Body Positive a self help group set up by and for gay men diagnosed sero-positive, recalled:

Everyone was in constant communication, it was mad, it was hectic [...] fundraising, visiting, a little bit of social life [...] Everything was HIV and AIDS, your whole life was taken over. All that incredible energy, just like gay lib and we were all contributing and feeding off it.⁸

This was also a strongly local response. There were networks of locally based groupings of gay men organising round the disease, often developing from existing gay organisations. There were local groups establishing

7 Berridge (1996).

8 Interview with Body Positive volunteer, quoted in Berridge (1995).

helplines, calling meetings, trying to obtain funding in places as far apart as Cardiff, Cambridge, Bristol, Brighton, Exeter. In London, groups such as Crusaid drew on the support of gay men who were not activist in any political sense, but who had equally developed a sense of community. This was a phase where voluntary organisations developed spontaneously on a largely self funded basis. It was ‘unambiguous voluntarism’ in the phrase used by Billis to describe that pattern of activity in the wider context of the voluntary sector as a whole.⁹

This response was therefore more than a political one. But its political dimension was highly significant. In Britain, the argument that the threat was to the heterosexual population was part of the political strategy of activists in the Terrence Higgins Trust (THT), the organisation which had been founded in memory of Terrence Higgins, one of the earliest men to die of HIV/AIDS in the UK. The Trust, like Body Positive, had originally been founded as a ‘pure’ self help organisation. In its initial incarnation, it had laid stress on fund raising for research, but later, it was re founded by gay men who came from the tradition of 1970s gay activism. It developed a different agenda. This laid less stress on funding research, and more on input to policy and the heterosexual threat posed by the syndrome. In stressing this threat, the Trust was part of an emergent ‘policy community’ which contained within it clinicians, scientists, and civil servants from within the Department of Health. That group reached the pinnacle of its policy influence in the autumn of 1986 when central government politicians adopted a high level crisis response to AIDS. This involved greatly increased public funding for research and services, together with a national mass media prevention campaign. In other countries, different political structures shaped different responses. In the US, for example, such direct political influence occurred more at the local level, and gay influence was directed in more defensive routes – resisting the closure of the bath houses or the testing of blood donors. In Australia, AIDS Councils, initially gay focused, and the Australian Federation of AIDS Organisations (AFAO) ensured community participation in HIV policy making and opposition to ‘medicalisation’ and the bringing of AIDS policies into the mainstream of public health responses.¹⁰ AIDS was defined as an issue of individual human rights rather than one of infection control as a result of these activities. In Britain, it was presented as a ‘national community’ issue, an epidemic which could potentially overwhelm the nation as a whole. Clearly the nature of this response was also conditioned by other factors, not least the strategies of the advertising agencies used for the mass media campaign; and the role of the media in conveying the tenets of epidemiology and the concept of ‘relative risk’ into the public domain. But it was arguably at this point that the influence of gay organisations was at its greatest. It was the

9 Billis (1989).

10 Berridge (2000).

strategy of the Terrence Higgins Trust in particular to deflect a potential anti gay public and policy backlash by stressing the heterosexual nature of the epidemic. In this strategy, the organisation was undoubtedly successful.

This generalised influence on policy making later focused more specifically on the issue of treatment and trials. Here there were some ironic developments. Gay men had rejected the ‘medical model’ of homosexuality in the 1970s, and in the early 1980s, many in gay circles had rejected warnings about the spread of ‘gay cancer’ out of a feeling that homosexuality could thereby be ‘remedicalized’. Yet the bulk of activist input eventually focused on just these medical issues. Gay men in western countries spent much effort in becoming ‘lay scientists’, in developing expertise about CD4 levels, about T cell counts, about combination therapies. Some gay men accepted the ultimate rationale of the need to ‘trial’ new drugs, or combinations, but sought to influence and inform how those trials were conducted. In both Britain and the US, activist input became axiomatic on trial and other committees considering treatment issues. As Edgar and Rothman point out, gay men argued that

the system of testing should not deny individuals the right to choose their own therapeutic options simply because scientists need controls in order to determine by their own canons of evidence what works best.¹¹

As a result, the design of the randomised controlled trial, the ‘gold standard’ of scientific objectivity in the post war period, was modified. Some trials ended early, most notably the US trial of AZT, and, in August, 1989, the US trial of AZT in early treatment. In Britain and elsewhere, the design of trials was modified to take account of activist objections to ‘unethical’ placebos. Gay activists such as Simon Watney attacked the ethics of the trials (as in the US), their secrecy and their use of placebos. Meurig Horton, a sero positive gay man, described an encounter in the Body Positive centre in Earls Court in 1988. MRC (Medical Research Council) researchers wanting to conduct the Concorde trial and prospective participants negotiated over the terms of that participation.¹² The use of preventive treatment for PCP (pneumocystis carinii pneumonia) and the use of ‘surrogate markers’, laboratory indications which were said to indicate the progress of the disease, were both rejected. Negotiation, participation and ‘patient power’ became the AIDS trial ethos. As a research director noted (in an interview with the author) “We can’t breathe with a retrovir trial now [...] The patient has got a lot to say in this particular disease area.”¹³

A later trial, the Alpha trial of DDI, offered an arm of the trial which simply randomised between high and low dose options, rather than high

11 Edgar/Rothman (1991).

12 Horton (1989).

13 Quoted in Berridge (1996), p. 188.

dose, low dose and placebo, as originally intended. Patients wanted to be sure that they were taking some form of treatment rather than nothing. Some critics argued that this led to trial results which meant little, if anything, in terms of demonstrated efficacy. In the US, such pressure also brought considerable changes in the regulatory structures established by the Food and Drug Administration (FDA). The ‘pharmacological Calvinism’ enshrined so that drugs like thalidomide would be kept off the market went into reverse under the impact of AIDS activism. As Edgar and Rothman wryly note, “large parts of the AIDS advocates’ critique of the FDA could have been scripted by the Pharmaceutical Manufacturers Association.”¹⁴ Patient participation became the treatment ethos as well, in the hospitals which were favoured on the gay information networks which grew up around the disease. The British immunologist and AIDS physician Tony Pinching remarked,

For general management the patient is the boss. They determine how they would like their care managed. You establish a common ground and explain what’s going on. You take whatever route you like, the high road or the low road [...]¹⁵.

AIDS saw the growth of a huge trials ‘industry’ in which lay input was also marked. Community representatives sat on the main trial committees reporting back through regular meetings to the trial participant community. Nick Partridge, head of the Terrence Higgins Trust, was a member of the MRC’s therapeutic trials committee and also of its committee on the ethics of AIDS vaccine trials which reported in 1991. In the following year, the AIDS ‘bible’, the *National AIDS Manual* drawn together and published by gay men, began to publish a substantial directory dealing with UK treatment and trials, later supplemented by a treatment update which gave the latest up to the minute information. In April 1993 for example *AIDS Treatment Update* devoted a special issue to the results of the Concorde trial and their meaning for the issue of early treatment. Gay writers such as Edward King and Keith Alcorn explained the implication for those taking AZT, the general finding that CD4 counts were of little use as surrogate markers of disease progression and the future of early intervention.

The Concorde findings make it seem increasingly unlikely that AZT will be widely used for long term treatment in asymptomatic people. More people with HIV may now choose to enter trials of combination therapy or of other drugs [...] Early intervention with effective anti-HIV drugs does still make theoretical sense. The limited usefulness of AZT for early intervention is likely to increase the pressure from people living with HIV and their advocates for other drugs to be rapidly and efficiently tested¹⁶.

Other groups took treatment activism further. ACTUP (AIDS Coalition to Unleash Power) originated in the US in 1987 and gained widespread

14 Edgar/Rothman (1991).

15 Pinching, Anthony, 1994 talk quoted in Berridge (1996), p. 188.

16 Alcorn/Gorna (1993)

support there with well-publicised ‘zaps’ on the National Institutes of Health, the FDA, CDC (Communicable Disease Centre) and with its slogan ‘Silence = Death’. In the UK its activities were more limited. Its arrival on the UK scene in 1990 was marked by a well publicised intervention at the annual meeting of the Wellcome Foundation, where activists sought a reduction in the price of Retrovir (AZT). ACTUP’s later activities included small scale guerrilla action against the oil multinational Texaco, a company which gave HIV tests to all employees and refused to employ those who were positive. It also harassed the Benneton clothing company, which had cynically used a photograph of a gay man dying of AIDS in an advertising campaign. It mounted a campaign which piggybacked onto the original ads. ‘There’s only one pullover this photo should be used to sell’ it argued, linking the original photo with a picture of a condom. The *National AIDS Manual* argued that an American style ACT-UP would be out of place in Britain, because of very different political traditions and structures.¹⁷

Such activism did not seek to challenge the traditional hegemony of biomedical science but rather to alter the ways in which it functioned. Other gay groups did challenge medical hegemony and this led to conflict within gay circles. Here one can see parallels with the conflicts between orthodox and alternative models in more distant history.¹⁸ For HIV/AIDS, the activities of Cass Mann and Positively Healthy epitomised the ‘alternative’ stance. Mann had been the manager of a gay club in New Bond Street, and had encountered AIDS (GRID in those days) in the US in the early 1980s. He co-founded Positively Healthy working through St Stephens Kobler Centre with Dietmar Bolle, a gay nurse with HIV who became a legendary figure in AIDS treatment circles and who died in 1992. One of Bolle’s obituaries commented

Positively Healthy had challenged conventional wisdom that diagnosis equals death, advocating instead self help, self worth and self determination, and the unbiased examination and evaluation of all conventional and alternative potential treatments and therapies. The early PH meetings were fuelled by his anger, principally directed at institutionalised fatalism over the course of this disease, and misdiagnosis and mistreatment of its many opportunistic infections.¹⁹

Mann seemed to excite either intense enthusiasm or equally intense opposition. The gay nurse leader Richard Wells, who was an enthusiast for a range of therapies in cancer treatment as well as AIDS, spoke with awe in an interview with the author of how he had seen Mann ‘energize’ a tomato by force of mesmeric power. But others were less enthusiastic. The Terrence Higgins Trust warned against the organisation in 1991 and said its advice should be treated with caution. Positively Healthy had by then adopted a

17 Quoted in Berridge (1996), p. 269.

18 Bynum/Porter (1987).

19 Clark (1992).

new name, 'Quack, Quack, Quack' and was promoting vitamins and food supplements.

Mann shared with the mainstream 'anti AIDS alliance' the view that HIV did not lead to AIDS, and was dubious about the value of AZT. Other gay groups also took up this argument. There was GAG (Gays against Genocide) in which Mann was a leading light, and SCAM (the Steering Committee on AIDS Malpractice), together with *Continuum*, a magazine founded to give publicity to all aspects of the anti-AIDs industry alliance. In 1993, members of GAG mounted a picket outside the THT offices to protest at their acceptance of money from the Wellcome Foundation for a series of leaflets which portrayed AZT in a favourable light. The instigators were later jailed for breaking an injunction preventing this picketing; they were planning posters denouncing 'AZT pimps' who promoted the drug at the expense of people with HIV and AIDS. Nick Partridge was quoted as calling them "new Age flat earthers who have a naive hope that Holland and Barrett will produce a herbal tea that will be effective against HIV." These were extreme examples of opposition between alternative and mainstream, but there was also a considerable degree of interrelationship with official therapy. Alternative therapies were on offer in AIDS centres like the Landmark and Lighthouse; massage and aromatherapy were part of the regular treatment package.²⁰ Here we can see the sorts of symbiotic interrelationships between orthodox and official which had also marked the more distant history of the two arenas.

Thus far, some significant victories for patient power – or so it seems at first sight. But was this really the case? The gains of the 1980s also opened up fragmentation about political and service strategies and some of the input into treatment and trials was shortlived. The policy influence of gay organisations at the period of intense crisis did not endure. So far as political strategies were concerned, initially gay men had adopted the 'national threat' strategy as a means of deflecting an anti gay backlash. By the 1990s, there was a feeling that the lack of a discriminatory 'risk group' focus had gone too far. Gay men were, so it was argued, in danger of being forgotten in the rush to warn others. In Britain, these struggles came to a head in 1992 over the issue of health education. A group, 'Gay Men Fighting AIDS' was formed out of the gay men's health education group of the Terrence Higgins Trust, which had been advising the government authority for health education, the Health Education Authority, about the tone and content of a gay focused campaign in pubs and clubs. The issue was one of power and control, but also about a new agenda for AIDS education, one which returned to the previously despised 'risk group' focus. Members of the group outlined this in a letter to the *Guardian Newspaper* with a look back to the early days:

20 Berridge (1996).

The needs of gay men have been neglected [...] The tragic irony is that contrary to public opinion, there hasn't been a 'gay lobby' during the AIDS crisis. Instead there has been an AIDS establishment which has sought to heterosexualize itself. After five years of 'de-gayng' of AIDS organizations and 'de-AIDSing' of gay politics, it is not surprising that less than 10 per cent of health authorities do adequate HIV education work aimed at gay men. Once again, as in the early 1980s, safer-sex educators are coming to the conclusion that the only people who can be trusted to look after gay men's interests in the AIDS crisis are gay men ourselves [...]²¹.

Some found themselves locked into a bureaucratic and service provision role, operating as arms of the state. The Australian gay sociologist Dennis Altman cited the example of the Australian AIDS Councils, which, as they became larger and better funded, became more and more like 'mini-health departments', with professional staff monopolising decision making. What had been created was a

very sophisticated and incestuous world of AIDS leaders [...] This group – of which I am a member – sits on proliferating government and non-government committees, which fly us around the country at an expanding rate, while rarely demanding that we account in any real way to the people for whom we allegedly speak.²²

Almost all AIDS specific organisations had come to reflect the dominant bureaucratic structures of the state in which they operated. In Britain, Tony Whitehead, one of the refounders of THT, criticised in a speech in 1988 the service delivery ethic which had led that organisation and others to focus on the provision of 'buddies'.

Instead of getting up and banging the table at those meetings as we should have done, instead of pulling the rug from under the government, we said, 'Yes, we must do something. We must strengthen the voluntary sector. Yes, we will do all we can to work with you.' [...] The work that the gay community has done in fighting section 28 of the 1988 Local Government Act has not been paralleled by any kind of direct challenge to the inadequacies of AIDS funding and government policies [...] Our immediate response to the tragedy of AIDS has been to rush off to hold people's hands at bedsides. We have not taken our fight out onto the streets as has happened in the United States [...]²³.

Such dilemmas were an inescapable part of all voluntary sector activity, not just for AIDS. They related to the activities of the state, which was coming to rely more and more on the voluntary sector to provide core services; partnerships with voluntary sector organisations were a general theme of government activity in health and social care in this period. For AIDS self help organisations, these dilemmas were compounded by a further raft of issues. In 1991 the collapse of Frontliners, a self help organisation for people with AIDS, highlighted a number of key issues, including the transition from self help to service provision. The urgency of the issue and the rapid advent of government funding had forced the organisation to

21 King (1992).

22 Altman (1993).

23 Whitehead (1989).

rush through stages of development – from birth to maturity, missing out childhood and adolescence altogether, as a government funded investigation put it.²⁴

For treatment and trials, too, there was change and a move back to more orthodox models. The imprecision of the Alpha trial results where activist intervention had modified the trial design, led to a return to methods which had operated previously. Even ACT-UP argued for the need for placebo controls. The Concorde results, which showed the advantages of results obtained over a longer time scale, also reaffirmed the medical rather than the activist model of trials.

The alternative medicine input into AIDS was also a source of fragmentation in the gay response. Those who sought to have input into treatment and trials essentially accepted a ‘medical model’, despite the fears of gay men at the start of the epidemic that GRID would lead to a ‘remedicalisation’ of homosexuality. Some gay men were in fact the most assiduous opponents of alternative approaches. The gay journalist Duncan Campbell was one such. In 1992, he won libel damages against the gay *Pink Paper* which so it was ruled, had defamed him in an article which criticised his opposition to Positively Healthy. This marked tensions between a mainstream gay and more radical oppositional stance to orthodox medicine.²⁵

To sum up, by the 1990s the earlier intense phase of influence of gay organisations on policy had ended. Organisations like the Terrence Higgins Trust were part of the regular organisational scene in the AIDS area, but they no longer had the central influence on policy they had had in the early days. And in other areas, too, treatment and trials for example, there was a move back to more orthodox models.

The move from self help to service provision with government support, downgraded the earlier political influence. Here was a variant of the classic voluntary sector dilemma, of activism versus incorporation.

Haemophiliacs

The victory for patient organisation was therefore more muted, contentions and subject to modification over time. But AIDS of course did not just affect gay men. Haemophiliacs and drug users were also part of the picture from the early years of the epidemic in the UK. Both groups played crucial roles in the articulation of a policy response. What was the role of patient organisation in these areas and how did it change under the impact of AIDS? For haemophilia, the role of organised voluntary activity was quite different to the gay activist organisations. Here was a different and more

24 Mortland/Legg (1991).

25 Berridge (1996).

orthodox model of voluntary sector organisation. In Britain, the Haemophilia Society, the main voluntary organisation, was long established; it had been set up in 1950. It had a paid secretary since the 1970s and appointed a paid AIDS coordinator in 1987.²⁶ Its ethos of voluntarism was quite different from the activism of some of the early gay organisations. AIDS was not the organisation's rationale. It had been thrust upon it; and the AIDS obituaries in the organisation's newsletter sat oddly beside the reports of very traditional volunteer fund raising activity in the localities. Members originally asked for information about AIDS to be given separately, and the organisation published the newsletter, *Haemofacts*, from 1984 to 1987. Its activism was of a different nature, expressed primarily through the campaign for compensation, which achieved a success of sorts in 1990, when agreement with government was finally reached. The haemophilia compensation case was a very traditional British single issue campaign, conducted by a traditional model of a British national voluntary organisation. The Society, as one member commented was 'not a voluntary organisation'. There was only one volunteer at headquarters, although there were volunteers in plenty out in the local groups. Nor was it anxious to prolong the AIDS connection. In general, the Society was anxious to leave behind the compensation battle, which had been divisive, and get back to concentrating on questions of health care and general haemophilia issues. By the mid 1990s AIDS figured little if at all in the Society's newsletter and new issues such as hepatitis C were centre stage.²⁷

There was no model of treatment activism in the organisation. The relationship of the haemophilia consultants with their patients had historically some similarities with gay men and the GUM clinics. There was an intense sense of commitment because of the long term and family connections engendered by the disease. But there the similarities ended. The arrival of Factor VIII in the 1970s had transformed the lives of haemophiliacs and consultants were anxious that those gains should not be lost in what was initially seen as a 'media panic' over blood products. The subsequent history of the blood issue in the UK is not the subject of this paper. But what does need noting in the context of patient power is the essentially paternalistic relationships which operated in this area. One consultant talked about

a close relationship between people with haemophilia and their doctor – he was almost like an uncle and may have known them all their lives. There is much guilt on the part of health care professionals – they gave their boys HIV. They prescribed factor VIII and in many cases even injected it [...]²⁸.

26 Foster (1990).

27 Berridge (1996).

28 Berridge (1996), p. 234.

It was notable that at a Wellcome ‘witness seminar’ on haemophilia not only did the discussion avoid HIV almost entirely but no ‘patient’ was present among the witnesses.²⁹ Despite the terrible impact of contaminated Factor VIII and HIV, haemophilia consultants were anxious to move on, and the episode does not appear to have disrupted essentially dependent patient relationships with the speciality. There was no activist self organisation round input into treatment on the part of haemophiliacs. They tended, too, not to advertise their condition.

Drug users

For illicit drugs, too, the issues for voluntarism and patient groups were quite different to those for gay men. As with haemophilia, there were already established voluntary organisations; in Britain the voluntary sector had played a major role in the provision of treatment since the late nineteenth century and had been increasingly drawn into policy circles since the 1970s. There was already a coordinating network organisation for the voluntary sector, SCODA, the Standing Conference on Drug Abuse, established in the early 1970s. Like the Haemophilia Society, it had its established parliamentary and lobbying links. Just as AIDS had forced some harsh reappraisals on the gay community, so, too, it did for the drug voluntary sector, where harm minimisation strategies and the possibilities of accepting and modifying injecting drug use, forced reassessments of the abstentionist policies of the drug rehabilitation communities. But harm minimisation had also initially emerged from grass roots initiatives in the voluntary sector.

In that sense, AIDS exposed existing divisions; and also added new complications. For several of the ‘new’ AIDS organisations, THT for example, took on drugs related support work, which caused some problems with the older organisations. Some there complained, too, that the AIDS bureaucratic machinery in the Department of Health dealt more readily with the ‘new’ organisations and their drug offshoots than with the ‘old’, who fed into the drugs section of the Department.

The longer ‘pre history’ of voluntarism for the drugs area was in some senses a complicating factor. In general, this was an area of ‘surrogate voluntarism’, like haemophilia, where activism was the province of paid workers. Many drugs workers were ex drug users, but the type of activism which had marked the early gay organisations was largely absent from the drugs area. Drug users themselves had few traditions of self organisation. Patient autonomy had been actively resisted by doctors who worked in the field, who tended to operate with standard models of treatment rather than through any accommodation to user needs and wants.

²⁹ Tansey/Christie/Reynolds (1999).

As for gay men, the impact of AIDS on drug users had contradictory tendencies. At one level, it led to a greater focus on harm reduction, on user friendly strategies, on attracting drug users into treatment rather than testing their resolve through restrictive policies and long waiting lists. But at another, it led to a greater reliance on medicalised solutions to drug use and a reaffirmation of the role of treatment. Paradoxically, but not surprisingly, given the medico-bureaucratic traditions of British drug policy, this came about in part through a move to destabilise the role of treatment. The Conservative Minister of Health, Brian Mawhinney, questioned the effectiveness of treatment and was keen to use the results of a national effectiveness study to question whether it was worthwhile. In the event, its outcomes were used to reaffirm the importance of the medical approach. Methadone prescribing (the substitute drug used instead of heroin) rocketed in the wake of AIDS; the AIDS 'new dawn' was represented by treatment and medical intervention. But there was little patient power in these twists and turns of policy and users seeking treatment diversity tended to use the private sector rather than the NHS. Only in the early years of the twenty first century did the issue of drug user self organisation and the influence of some new 'user groups' begin to rise. Here it can perhaps be argued that the earlier example of gay self organisation had a longer term policy impact on the drugs field, and indeed, some of the user groups did develop out of those originally specific to drug users with HIV.

Conclusion

At the beginning of the paper, I identified different forms and models of organisational 'patient power' which had developed since the 1960s: activism to improve services, single issue political campaigns, and self help/alternative medicine groups. The conclusion would be that AIDS did show significant advances in patient input and in health voluntarism in these areas so far as gay men were concerned. AIDS opened up a new area of activism round the research process and especially the randomised controlled trial. In general it also gave impetus to research ethics and human rights views of research and treatment, with a greater emphasis on consulting participants and on informed consent. But patient preference arms in trials did not prosper and some commentators³⁰ have argued that the ethical developments represented an extension of medical self regulation, a further extension of medical control. In other areas – haemophilia and drug use – the role of patient organisation was much more muted and bore no comparison to that of the educated and articulate urban middle class gay men.³¹ If one looks across the 'AIDS arena' – AIDS treatment and trials, haemophilia medication, the response to drug users – one can see some advances for the 'patient consumerism' and health

30 Cooter (1995).

31 Epstein (1996).

activism which had its origins in the 1970s. One can also see a greater reliance by government on such organisations as a conduit for service provision at a time when government in general in the UK was formalising its relationships with voluntary sector organisations. It was this dilemma for organised groups which Tony Whitehead recognised in his comments in the late 1980s. Influence and funding brought incorporation and loss of independence, a classic dilemma for the voluntary sector. One can also see an intensification and development of the ‘medical model’ which some of the earlier gay campaigners had feared would be the impact of AIDS. For gay men, haemophiliacs and for drug users, new policy responses were framed round pharmaceutical responses to this public health issue. This was a new variant of public health which came to characterise turn of the century health policy in other areas as well. It had as its focus treatment as a preventive strategy, as for example, through the increased reliance on methadone in drug treatment/prevention. This was a ‘new pharmaceutical public health’.³² Activist organisation and consumerism were important forces in these developments, but were placed within a subordinate rather than a determining role.

32 Berridge/Loughlin (forthcoming).

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