

TABLE II—Referral pattern from specialists, 1984-7

Specialty	1984 (n=121)	1985 (n=164)	1986 (n=255)	1987 (n=285)
Oncology	4	7	19	15
Radiotherapy	12	22	40	81
Surgery	31	72	135	103
General medicine	74	63	61	86

Reason for referral:
 Symptom control 179 patients
 Psychological support 59 patients
 Home care support 32 patients
 Other (hospice advice, dressings, staff support) 12 patients

As a direct result of this study the City and Hackney Area Health Authority set up a working party to look at the feasibility of having a specialist, multidisciplinary team to advise about symptom control and to support the terminally ill patient and his or her family. The creation of a specific unit for the terminally ill was rejected in favour of "working alongside" the consultants in charge when invited to. The team would thus be able to disseminate their skills more widely to all grades of doctors and nurses. Being an advisory service enables consultants to "use" the team whenever there is a need without waiting until a decision has been made to discontinue curative treatment. The team now has a complement of one full time doctor, three full time nurse specialists (two based at our hospital, one based at Hackney/Homerton Hospital), one part time social worker, and one secretary.

The numbers of patients referred to the team have gradually increased (see table II), showing that the team is accepted by most of

the consultants. The main reason for referring most patients continues to be palliation of symptoms from advanced cancer (see table II). The team is concerned with half of the total number of patients who die of cancer at this hospital. The number of patients who are referred with non-malignant disease is increasing.

A more objective measure of the effect of the team is the dramatic reduction in the number of complaints relating to "terminal care." In 1983, 14 complaints were received from relatives who had been dissatisfied with the care of close relatives (8.6% of 163 complaints received). In 1985—one year after the introduction of an advisory service—complaints about the care of the dying in hospital had dropped to five, and in 1987 there were two.

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Syringe exchange schemes for drug users in England and Scotland

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Abstract

In 1987 experimental schemes for distributing injecting equipment to intravenous drug users to help prevent the spread of the human immunodeficiency virus were started by the government. After six months the schemes were found to have been reasonably successful in attracting clients but were less successful in keeping them. It has been shown that equipment can be distributed to drug users on an exchange basis. Many of the clients who were attracted to these schemes had had no treatment or other help for their drug problems.

Introduction

In April 1987 the government launched pilot schemes to attempt to reduce the spread of infection with the human immunodeficiency virus (HIV) among intravenous drug users by making injecting

equipment available to them, together with advice on drug use and safer sex. These are commonly known as "syringe exchange schemes." The government took this step because of reports of high rates of HIV infection among some groups of intravenous drug users. The highest known rates of HIV antibody seropositivity in intravenous drug users are in Edinburgh, where between 1983 and 1985 half of the 164 heroin users tested seropositive.¹ In other large cities known rates are much lower. In Glasgow 4.5% was recorded in 1985,² and rates of between 0 and 10% have recently been reported in different English cities.^{3,4} While the potential spread of infection with HIV is a serious problem, in many areas there is time to try to prevent it.

In England the Department of Health and Social Security invited drug agencies to set up pilot schemes for one year, offering some financial support for that first year. In Scotland the Scottish Home and Health Department asked health boards to set up the schemes. The DHSS asked potential participating agencies to provide (a) injecting equipment on an exchange basis to drug abusers who were already injecting and unable or unwilling to stop; (b) assessment of and counselling for clients' drug problems; (c) advice on safer sex and counselling on HIV testing. The Scottish schemes included medical staff.

Research design

We were asked by the DHSS and the SHHD to monitor (a) the implementation of the schemes by looking at the organisation of schemes, nature of treatment and counselling provided, numbers

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and characteristics of clients, reasons for participation, numbers of needles and syringes issued and returned, and problems with compliance, and (b) the impact of the schemes by looking at the changes in numbers and characteristics of clients presenting to agencies, changes in clients' knowledge and attitudes to AIDS and HIV, reported changes in drug use and injecting behaviour, and reported changes in sexual behaviour. Information is collected (a) on the location, staffing, costs, working methods, and philosophy of the agencies; (b) on all clients at intake on a brief intake sheet; (c) on clients' behaviour, attitudes, and knowledge with respect to HIV by means of the first client questionnaire, which is administered during the first month of attendance; and (d) numbers of syringes distributed and returned and dates of visits on a syringe exchange form. Thus far we have examined how the schemes operate. The data reported cover the first six months of the schemes from April to October 1987 and are based on the intake sheet (n=769) and the first client questionnaire (n=186).

Findings

Fifteen schemes were set up, one has since closed but is included in the analysis, eight were both operational and able to start collecting data in June 1987, and the last scheme started in September 1987. Delays were caused by problems in finding suitable staff and premises, uncertainties about local funding, and objections from local residents. Some schemes are linked to outpatient drug dependency clinics, others are in drug advice and information agencies, but most are in separate premises. In one scheme local pharmacists distribute equipment. One scheme started in the accident and emergency department of a large city hospital. Most are open during office hours, but not all are open every day.

Attracting clients—Since the schemes started about 1800 clients have attended at least once. A total of 769 clients attended between June, when monitoring started, and the end of October 1987—that is, 63 operating months. There was a wide variation in case load. Three agencies had fewer than 10 clients, and in the largest schemes between 20 and 50 clients attended each day (table I). Most clients (98/180; 54%) travelled two miles or less to their scheme.

Age and sex—The mean age of clients was 26.8, but there was a wide non-normal age distribution, with a range from 17 to 52. The schemes attracted some younger clients (294/718; 41%) aged 24 or under. Six hundred clients (78%) were men and 169 (22%) were women.

Age at first injection—The mean age at first injection was 19.1, the modal age was 16, and 118 out of 182 (63%) clients had their first injection at 19 or under. The average length of time between first injection and entering the scheme was 7.7 years.

Drugs used—Heroin (418; 57%), methadone (95; 13%), and other opiates (37; 5%) were the preferred drugs, but some clients reported that amphetamine (125; 17%) was the main drug used (n=734).

TABLE I—Numbers of clients who attended each agency

Agency	No before monitoring began	No monitored (June-end October)	Total
A	—	74	74
B	—	99	99
C	—	6	6
D	71	66	137
E	—	67	67
F	—	67	67
G	—	5	5
H	—	59	59
I	579	115	694
J	300	94	394
K	14	22	36
L	—	17	17
M	52	28	80
N	—	7	7
O	—	43	43
Total	1016	769	1785

TABLE II—Differences among agencies in client return rates

Agency	No	Percentage who returned for:			
		2nd visit	3rd visit	4th visit	5th visit or more
A	69	57	33	25	16
B	91	78	55	48	40
C	6	67	50	17	17
D 1*	37	59	30	24	11
D 2*	29	52	28	17	14
E	67	70	48	40	33
F	63	27	13	5	3
G	5	60	20	20	—
H	29	55	48	38	35
I	51	82	69	63	61
J	81	85	73	65	62
K	15	53	27	20	20
L	16	75	38	38	38
M	21	86	81	81	81
N	2	50	—	—	—
O	39	80	56	49	41
Total	621	66	47	40	34

*Operating on two sites.

Clients were multiple drug users, having used a wide range of their drugs in the past four weeks. Of importance is that half (94/182) had injected amphetamine, and some had injected methadone (62/181; 34%), cocaine (23/181; 13%), barbiturates (22/180; 12%), and tranquilisers (28/178; 16%).

Previous treatment and help—Most clients were not being treated for their drug problems: of 695 clients, 216 (31%) had had no previous treatment, 243 (35%) had had previous treatment, and 236 (34%) were being treated. Most had had no help for their drug use from a social worker (132/179; 74%), probation officer (93/181; 51%), drug dependence unit (95/180; 53%), outpatient department (111/180; 62%), inpatient detoxification unit (123/181; 68%) or other inpatient treatment unit (102/180; 57%), therapeutic or residential community (123/180; 68%), private clinic (160/179; 89%) or private doctor (135/180; 75%), self help group (135/181; 75%), or accident and emergency department (98/181; 54%). (All figures taken from the first client questionnaire.)

Client retention—There was a high dropout rate, with 211 out of 621 clients (34%) making one visit only and 329 (53%) making two visits only (table II).

Clients lost—We compared a subset of clients who attended once only against those who made more than one visit (those for whom attendance data were not available at that time are excluded). Clients who attended once only were slightly younger (mean (SD) 25.9 (5.5) years, n=132 against 27.3 (6.5) years, n=379, p=0.031). They were also more likely to have had no previous treatment (181, 41% against 419, 28%, p=0.001). There was a trend to a slightly shorter elapsed time since their first injection (mean 7.1 (5.3) years, n=120 against 8.0 (5.7), n=344, p=0.152).

Reasons for attendance—On the first visit over half of the 728 clients (408; 56%) reported that worry about AIDS was a reason for attending, and this was followed by scarcity of equipment (277; 38%). Of 680 clients, most had previously obtained equipment from pharmacists (388; 57%) or friends (204; 30%) (this is not an indication of the adequacy of previous supply). Of 686 clients, 418 (61%) were regular injectors injecting six or seven days a week, 199 (29%) were casual injectors injecting two to five days a week, and 69 (10%) injected weekly or less often.

Supply and exchange of injecting equipment—All agencies offered a choice of syringe and needle sizes, all (except one) supplied condoms and swabs, and four supplied sterile water. Supplies were free to clients except when distributed by pharmacists. Clients were given an average of seven syringes per visit, range one to over 100. Four schemes provide a container in which to return equipment. If the container cannot be safely opened for a visual check then the client's verbal report is taken. Clients deposit loose equipment in a safe container for later destruction. Staff then issue new equipment on roughly a one to one basis. The average exchange rate was 78%, which included equipment issued to clients who did not return (table III).

Counselling—Agencies were advised to counsel intravenous drug users and supply equipment only to those who were unable or unwilling to stop. In most agencies little counselling is carried out at the first contact, and staff consider it unwise to attempt too much too early in their relationship with clients. All agencies counsel clients about reducing the risk of transmitting HIV by changing behaviour. Three agencies operate an explicit harm minimisation approach, which is aimed at reducing the general health hazards from injecting.

TABLE III—Differences among agencies in the distribution and exchange of syringes

Agency	No of clients	No of visits	No of syringes issued	Mean No of syringes issued per visit	No of syringes returned	Exchange rate (%)
A	69	174	1 349	8	543	40
B	91	446	606	1	305	50
C	6	15	95	6	44	46
D 1*	37	92	105	1	91	87
D 2*	29	66	63	1	68	108
E	67	281	830	3	282	34
F	63	100	264	3	108	41
G	5	10	49	5	15	31
H	29	110	406	4	192	47
I	51	619	8 583	14	8 860	103
J	81	884	7 239	8	6 364	88
K	15	44	1 384	31	441	32
L	16	57	424	7	336	79
M	21	342	815	2	244	30
N	2	3	17	6	—	—
O	39	207	2 061	10	1 123	55
Total	621	3 450	24 290	7	19 016	78

*Operating on two sites.

Preliminary assessment

Many schemes have been operating for a short time only and are still establishing their reputations and working practices. Most clients claimed that opiates were the main drugs used, but the schemes were also attracting some primary amphetamine injectors, and over half had injected amphetamine in the past four weeks. The schemes tended to attract older (over 24), long term injectors, and there were fewer women than are normally found in such groups.^{5,7} They are reaching groups of clients who are not reached by other services for drug users. Nearly one third had had no treatment for drug problems, and a third had no current contact with drug treatment services. Overall little use was made of a broad range of other services for drug problems. The schemes are not successful in attracting some intravenous drug users who should be reached in an HIV prevention strategy. Target groups should include younger people with a shorter duration of drug use by injection and women. The dropout rate was higher than expected and raises questions of how schemes might be changed to hold on to clients and maximise the benefits of the first contact. Of particular concern is the loss of young clients who have had no treatment.

On average, clients received seven syringes at each visit. Perhaps more generous supplies should be given out. The average rate of exchange of equipment was 78%, but this varied greatly among agencies. There may be a conflict between aiming for a high return rate to control infection and not wishing to deter clients. If client retention is improved schemes should aim at improving on the exchange of equipment in view of the health risks and problems that may follow if discarded syringes are found in public places.

The extent, intensity, and quality of counselling were extremely variable. Some agencies had developed clear strategies for counselling, others have yet to do this. The effectiveness of different counselling strategies is not known. Many workers in agencies and clients find it harder to discuss sexual practices than to discuss drugs. Schemes vary in the character of the relationship between staff and clients—that is, “user friendliness.” In many schemes staff are non-judgmental and avoid the coerciveness that typifies many encounters between clients and professionals. Though many staff

are dedicated, hardworking, and enthusiastic, there is always a danger of fatigue and disillusionment. Support is needed locally and nationally.

The task of trying to reduce the spread of HIV requires staff to encourage clients not to share injecting equipment and to adopt safer sexual behaviour. In some agencies staff have begun to rethink the character of their work with drug users. Some workers are also engaged in a more general harm minimisation approach, which entails counselling in “safer drug use,” sometimes including advice about injection sites and techniques. Others have doubts about teaching drug users how to inject. Their doubts must be placed in the context of the way in which British drug treatment policy has developed in the past few years, which has been oriented to contract therapy and abstinence.⁸ It is difficult for some who work with drug users to adopt the style of work required for harm minimisation.

Many needs of clients are not being met by others—for example, primary health care is lacking for many drug injectors, as are social welfare and help with drug related problems. Some agencies spend much time trying to get such help for clients, and several are considering introducing primary medical care services.

In most agencies syringe exchanges are carried out separately from other services. Syringe exchange schemes need the support of specialist workers and are not a substitute for other services. These schemes can be seen as a “low threshold” contact point for drug users within the local health and social services. The results of our study suggest that these schemes may become a new tier of services for drug users that reaches those who are not reached by other services.

The schemes must make an effort to attract clients. The characteristics of a successful scheme should become clearer as they develop. We think that schemes that are successful in attracting and keeping clients (a) are located in areas with a high prevalence of injecting; (b) have ease of access, both physical and psychological; (c) have staff who are non-judgmental; and (d) have informal working relationships with clients. New schemes being set up should be publicised carefully to establish their reputation with drug injectors, receive local administrative support, keep good records on client groups, client retention, and syringe exchange rates, have suitable opening hours, maintain good relations with the local media, police, and community groups, have clear goals and objectives, and issue adequate supplies of injecting equipment.

We do not know whether these schemes are encouraging intravenous drug users to change from behaviour that may spread HIV, but we plan to study this aspect.

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